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KAREN TREISMAN BA

**THE EXPERIENCES AND MEANING FOR UK-BASED AFRICAN WOMEN
AFTER BEING DIAGNOSED WITH HIV DURING THEIR PREGNANCY**

Section A: A literature review on the experience for mothers of being diagnosed and living with HIV, with a particular focus on African mothers

Word Count- 5471

Word Count with references- 9545

Section B: The meaning and experiences for UK-based African women after being diagnosed with HIV during their pregnancy, and their subsequent coping strategies.

Word Count-7986

Word Count with references- 10,107

Section C: Critical Appraisal

Word Count- 1997

Word Count with references- 2346

Overall Word Count- 15,347

Acknowledgements

I would like to use this opportunity to firstly thank all of the women who took part in this study. I felt honoured to hear your stories and inspired by your courage, openness and capacity for resilience. I would also like to thank Jessica Rwami, whom has been incredibly supportive throughout this project and continually reminded me of why I wanted to study this group of women. She is someone who has touched so many lives, including my own, and I am so grateful for her knowledge, strength, generosity and friendship. I would also like to acknowledge the team at Embrace UK for their encouragement, support, flexibility and use of their rooms.

To my supervisor, Dr Liz Shaw, thank you for helping me to bring some initial ideas to fruition, for providing/introducing me to wonderful contacts, for suggesting interesting sections of literature, and for re-connecting me with my passion for the area studied. To my other supervisor, Dr Fergal Jones, thank you so much for all you have done. I have felt so valued, contained and held throughout these 3 years, and your encouragement has been unwavering. Thank you so much for reading each section and taking care, time, and thought to reflect on it all. I feel forever I will have an internal Fergal dialogue 😊 when writing things up or carrying out future research. I would also like to extend my thanks to the Salomons library and admin staff who have been fantastic throughout.

To my colleagues/friends at Salomons I can't begin to express the difference you have made to these 3 years and this project in particular. There are too many people to mention here, however I would like to say a huge thank you and masses of appreciation to 2 of my closest friends, Savina Wachter and Ayo Sodeke-Gregson. They have gone above and beyond throughout, and have always offered me endless support and encouragement. They have read numerous versions of this project, given invaluable feedback and suggestions, and at the same time have been there as incredible friends. Without them and their brilliant editing skills this project would not have been possible.

Lastly to my family, my parents, Binnie and Hylton, and my sisters, Nicky and Loren, my whole life you all have been my cheer leaders, and continually encouraged and supported me. Your unconditional love and patience has been invaluable and I feel very blessed to have you all in my lives. Thanks for always having faith in me and for supporting and helping me to achieve my goals! I love you.

SUMMARY OF PORTFOLIO

Section A provides a conceptual critical review of the literature pertinent to the consideration of Mothers living with HIV/AIDS (MLWHA), with a particular focus on African mothers. This review will first highlight relevant contextual factors, including discussing prevalence rates and the current reconceptualisations of HIV. This is followed by theories and research relevant to MLWHA, whilst considering wider contextual, social and cultural factors. Thirdly, the theoretical links of the reviewed literature to coping models and strategies are made, and specific cultural factors considered. Finally, suggestions for future research are highlighted.

Section B provides the findings of an Interpretative Phenomenological Analysis (IPA) study exploring the meaning, experience and sense-making for UK-based African women who are diagnosed with HIV during their pregnancy. Individual semi-structured interviews were conducted with 12 African women, aged between 23-41, who were diagnosed with HIV during their pregnancy. Emerging master and sub-themes are presented and examined, followed by a discussion of the clinical implications, future research ideas and methodological strengths and limitations.

Section C provides a critical appraisal and reflection on the research process, including, evaluating what research skills were learned, which research skills the researcher wishes to develop in the future, what would the researcher have done differently given the chance, how will the research shape or inform the researcher's clinical practice, and what future research related to the studied area would the researcher consider carrying out.

Summary of Abbreviations

MLWHA- Mothers living with HIV/AIDS

WLWHA- Women living with HIV/AIDS

PLWHA- People living with HIV/AIDS

MTCT- Mother-to-child-transmission

QoL- Quality of life

IRM- Illness Representations Model

HAART- Highly active antiretroviral therapy

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SECTION A: LITERATURE REVIEW

A literature review on the experience for mothers of being diagnosed and living with

HIV, with a focus on African mothers

Word Count- 5471

Word Count with abstract and references- 9545

Abstract:

This paper presents a conceptual critical review of the literature pertinent to the consideration of Mothers living with HIV/AIDS (MLWHA), with a particular focus on African mothers. The review first highlights the relevant contextual factors, the current re-conceptualisations of HIV and the potential mental health consequences of a diagnosis of HIV. This is followed by theories and research relevant to MLWHA, whilst considering wider contextual, social and cultural factors. Thirdly, the theoretical links of the reviewed literature to coping models and strategies are made, and specific cultural factors considered. Finally, suggestions for future research are highlighted.

1. INTRODUCTION

This review presents literature relevant to the impact for mothers of receiving and living with a diagnosis of human immunodeficiency virus (HIV), with a specific focus on African mothers.

A review is warranted as research suggests that women living with HIV/AIDS (WLWHA) are a unique population owing to their biological, economic, and social vulnerability to contracting HIV (Baingana, Thomas, & Comblain, 2005) and due to most women being in their reproductive years (UN-AIDS, 2007).

Being a mother living with HIV/AIDS (MLWHA) brings challenges which may lead to increased levels of distress and depression (Murphy et al., 2002), impact the mother-child relationship, and on the child's overall development (Shonkoff & Phillips, 2000). Furthermore, MLWHA are often the primary caregivers in a family constellation (Bor & duPlessis, 1997), may experience guilt about the impact of HIV/AIDS on the family (Goggin et al., 2001), and have concerns about their children's needs and financial struggles (DeMatteo, Wells, Goldie, & King, 2002). Furthermore, they may have to contend with stigma, socially constructed roles, gender inequalities (Dodd et al., 2004), reproductive decision-making (De Bruyn, 2004), and threats to their sexuality (Weitz, 1990).

Existing literature on MLWHA predominantly focuses on an American sample, and on women who have contracted HIV through drug-use. Furthermore quantitative studies tend to investigate avenues around sexual risk behaviours, transmission routes (Arendt & von Giese, 2003), differences between ethnicities in HIV-presentation (Boyd et al., 2005), pathways to HIV testing (Erwin et al., 2002), and adherence to highly active antiretroviral therapy (HAART) (Mellins et al., 2008).

Therefore this review will take a different angle, and focus on the psychosocial lived experience of African MLWHA within a UK context. People of African origin are the second largest identifiable group of HIV-positive service-users in the NHS, yet remain underrepresented in the literature (Kesby, Fenton, Boyle, & Power, 2003). Moreover, relatively little has been written about people from ethnic minority backgrounds within the British context (Brown, 2000). Literature suggests that African MLWHA may contend with additional challenges and require further consideration due to various cultural and social factors (Dodd et al., 2004).

In order to consider a multi-faceted picture of the experience of MLWHA, with particular attention to African mothers, several threads and key areas will be systematically explored and synthesised. Some relevant literature exploring MLWHA from non-African populations will be discussed in order to capture some of the more general themes impacting on MLWHA, and to highlight gaps in the African specific literature, and to lend itself to potential future research ideas.

With the intention of providing an overview, this review will highlight relevant contextual factors, including discussing prevalence rates, the current re-conceptualisation of HIV as a chronic condition, and the potential implications of being diagnosed with HIV. This will be followed by theories and research relevant to MLWHA in general, whilst considering more specific contextual, social and cultural factors for African MLWHA. Theoretical links between the reviewed literature and coping models will be made and cultural factors considered. Finally, suggestions for future research will be highlighted.

2. HUMAN IMMUNODEFICIENCY VIRUS (HIV)

HIV is a viral infection that can lead to Acquired Immunodeficiency Syndrome (AIDS). The four major routes of transmission are from an infected mother to her baby during birth, through breast milk, unprotected sex, and contaminated needles. HIV damages the immune system, particularly white blood cells known as CD4 cells. Furthermore, three-quarters of individuals diagnosed with HIV/AIDS experience cognitive and neurological changes, with 30% exhibiting multiple lesions in their central nervous system (Stern, Perkins, & Evans, 2000).

2.1 UK prevalence

In 2010, the estimated cumulative total in the UK was 111,922 HIV/AIDS cases, with a further 27% predicted to be unaware of their status (HPA, 2010).

UNAIDS (2004) indicated that HIV has reached an epidemic status, and is particularly on the rise among women, with an approximated 18:5 women-to-men ratio among 15 to 24-year-olds (HPA, 2010). In the UK, females account for 37% of new HIV diagnoses (HPA, 2010). Eight percent of children born in the UK to MLWHA were infected, with the remainder being described as affected by HIV (HPA, 2010). However, this data were obtained from an anonymous prevalence monitoring programme, thus limiting the validity. Furthermore, statistics utilise broad ethnic categories, which often fail to distinguish between nationalities, potentially resulting in conservative estimates (DeCock & Low, 2007).

2.2 HIV as a chronic condition

In the Western world, medical advancements and the availability of HAART have led to HIV/AIDS being re-conceptualised from an acute illness to a chronic

condition (Clarke, 1994). This has resulted in economical and cultural repercussions for the available treatment and public understanding of HIV/AIDS (Scandlyn, 2000). However in the public realm this shift is arguably less known (Jack, 2010). With increased life expectancy, more attention is being paid to the quality of life (QoL) and mental health of people living with HIV/AIDS (PLWHA).

2.3 Mental health and HIV/AIDS

HIV/AIDS has vocational, psychological, and social implications (Satriano, Berkman, & Remien, 2005), which can place extreme demands on one's coping skills and mental health (Basavaraj, Navya, & Rashmi, 2010). HIV/AIDS often becomes an enduring stressor for relationships, the individual and their family (Weihs, Fisher, & Baird, 2002), and can take on a master status obliterating the identity of the person (Goffman, 1963).

A diagnosis of HIV can lead to self-blame, anger, guilt, hopelessness, denial, disclosure fears, low self-esteem, isolation, and depression (Stevens & Hildebrandt, 2006). Furthermore, the implications of a life-threatening illness diagnosis are considered a possible traumatic stressor within the DSM-IV (American Psychiatric Association, 2000).

The World Health Organization (WHO, 2001) asserts that the mental health consequences of HIV/AIDS are substantial. Gallego, Gordillo, and Catalan (2000) stated that 38-73% of PLWHA will have at least one psychiatric disorder in their lifetime, and Benton (2008) found that 1/3 will have mood disorders. HIV has been associated with acute stress, trauma (Israelski et al., 2004), panic, increased body-scanning, and generalized anxiety (Treisman, Fishman, & Lyketsos, 1994). Moreover,

a UK study found that 31% of PLWHA reported having suicidal thoughts in the previous week, with heterosexual men, those who had not disclosed their status, and people of black ethnicity, being twice as likely to have such thoughts compared to other groups (Sherr et al., 2008).

2.4 HIV-positive people from ethnic minority backgrounds in the UK

Although the term “African” will be used, it is acknowledged that this unfortunately implies homogeneity within a heterogeneous group of individuals comprising of numerous cultures, languages, tribes, religions, nationalities and ethnicities (Elam, Fenton & Johnson, 1999). Flowers et al. (2006) interviewed 30 UK-based Black-African people, and reported that the level of isolation and poverty requires a re-contextualisation of the HIV experience. This population may include asylum-seeking or refugee people, whose needs are multi-faceted and multi-dimensional (Papadopoulos, 2001) and may cover the entire spectrum of human requirements. They may have to justify their presence, whilst living in legal limbo (Luebben, 2003), and under the ever-present threat of being repatriated (Sourander, 2003).

Moreover, they may experience a myriad of psychosocial difficulties, including language barriers, housing, and unemployment. A large-scale study of outpatient HIV-care in London (N=1,687) found that African HIV-positive service-users reported more social difficulties than any other group (Ibrahim, Anderson, Bukutu & Elford, 2008). This illustrates some of the social and economic challenges faced, however as acknowledged by the authors, the findings are based on self-reported data, and may be affected by social desirability bias and/or confidentiality concerns.

Moreover, many have experienced traumas and losses. Forsyth, Burns, and French (2005) found, from a sample of 656 African individuals from 34 countries, that UK presentation patterns of HIV correlated with periods of conflict and political unrest in one's country of origin. For example, the female HIV-prevalence in Rwanda prior to the 1994 conflict was 1%, which rose to 11% by 1997, when an estimated 3% of all Rwandan women had been raped (UNAIDS/ WHO, 2003). However, these findings should be interpreted with caution as the trends are descriptive and therefore a statistical correlation can not be made.

In addition, Mann (1996) suggested that PLWHA, particularly those from minority backgrounds experience human rights violations. Mann (1996) identified three phases of the HIV/AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial. Dodd et al. (2004, p.25) supported this notion, "social, political and institutional racism are compounded by anti-asylum discourses which construct African people as threatening to the UK, through their capacity to spread disease and drain government resources".

2.5 Summary:

MLWHA are a unique under researched population amongst PLWHA with varying challenges to their wellbeing. With increasing prevalence rates, HIV re-conceptualised as a chronic condition, and the widely acknowledged implications of a diagnosis on the individual and their family, further understanding of their unique needs and QoL issues may be valuable. Having outlined the broader context, this review will now discuss literature relating to HIV in the context of motherhood.

A comprehensive literature review was undertaken; See Appendix 1 for the full search strategy and for information relating to how the studies included were selected and deemed appropriate.

HIV IN THE CONTEXT OF MOTHERHOOD

3.1 Early detection and prevention measures in pregnancy

Before exploring the experience of being a MLWHA and some of the additional considerations for African mothers, it is important to provide some relevant context. In 1999, the UK adopted an “opt out” policy approach to antenatal HIV-screening at around 12-weeks of gestation (Department of Health, 1999). This has led to significant reductions in the UK of mother-to-child-transmissions (MTCT) of HIV, which can occur during pregnancy, labour, or through breastfeeding, and approximately 90% of HIV infections being detected before delivery (HPA, 2009). These reductions have mainly been achieved through antiretroviral drugs, not breastfeeding, and, where appropriate, a caesarean section (DoH, 1999).

It has been estimated that without treatment, around 15-30% of babies born to HIV-positive women would become infected during pregnancy and delivery, with a further 5-20% becoming infected through breastfeeding (De Cock et al., 2000). With treatment, the risk of MTCT is estimated to reduce to 1% (Coovadia, 2004). Therefore, pregnant women represent an important group of PLWHA (Smith et al., 2009) due to early intervention and MTCT prevention opportunities, and due to the unique challenges they face, which will be discussed in the following sections.

3.2 Cultural considerations of MTCT HIV prevention

The recommended steps to reduce MTCT (DoH, 1999a), coupled with the cultural expectations surrounding birth and pregnancy, and the UK becoming increasingly medicalised (Uskul & Ahmad, 2003), has instigated questions about how MTCT prevention measures might conflict with cultural practices and norms (De-Sammy, 2006). The following studies illustrate cultural considerations relevant to MLWHA. Breastfeeding will be the main focus in this review, as it is considered a fundamental component of the maternal role in African women (Hilderbrand, Goemaere, & Coetzee, 2003).

Hilderbrand et al. (2003) found that African MLWHA perceived breastfeeding as crucial for developing an emotional bond with the baby, and key in ensuring nutritional health (Piwoz et al., 2005). Therefore they experienced guilt, frustration and sadness as a result of not breastfeeding. In some cultures, opting for a caesarean or bottle-feeding can arouse suspicion and create stigma, owing to the association of such behaviours with HIV, and the cultural beliefs that HIV is caused by promiscuity (Eide et al., 2006).

Thairu et al. (2005) used ethnographic techniques to interview 22 South African HIV-positive women about their views on infant-feeding. Five themes of influences on feeding decisions emerged: (1) stigma; (2) maternal age and family influences on feeding practices; (3) economic circumstances; (4) beliefs about HIV transmission through breastmilk; and (5) beliefs about the quality of breastmilk compared to formula. Similarly, Doherty et al. (2006) interviewed 40 African HIV-positive women to explore infant-feeding practices, and concluded that fear of

disclosure and stigma weakened mothers' ability to resist entrenched community and family norms.

Kebaabetswe (2007) carried out qualitative interviews exploring the factors motivating and hindering pregnant women's participation in a MTCT prevention programme in Botswana. Participants included ten HIV-positive pregnant women who took part in the programme, 11 who declined the programme, 9 health workers and 10 key informants. Thematic content analysis suggested that fear of knowing one's status, stigma, lack of male partner's support, and negative attitudes of health workers were barriers to participation; whereas availability of free antiretroviral drugs and infant formula were reinforcing factors. This study is noteworthy as it attended to multiple perspectives, including those who declined the intervention.

The above studies are limited by the lack of quantitative data, and by small and purposive sampling, which may not be representative of other sub-populations. Nevertheless, they illustrate that limited resources, stigma, and discrimination are significant impediments to these women, and that going against cultural feeding norms can reveal the mother's HIV-status, resulting in unwanted disclosure and discreditation of motherhood.

3.3 Becoming a mother

General theoretical underpinnings and conceptual frameworks on becoming a mother are discussed below, before proceeding to the experience of MLWHA.

Childbearing can be a period of psychological transition, which can be helpfully understood within a social context (Wrede et al., 2006). Furthermore, becoming a mother represents significant personal, social and biological transitions

(Smith, Flowers, & Larkin, 2009), with the birth of a child being identified as a major life event for the family (Weaver & Usher, 1997). Mercer (2004) described becoming a mother in four stages: 1) commitment, attachment and preparation, 2) acquaintance, learning, and physical restoration; 3) moving toward a new normality, and 4) achievement of a maternal identity. Furthermore, Sethi (1995) posited that becoming a mother involves constant change, including redefinitions of self, relationships, and professional goals.

These complexities were captured in a meta-synthesis of nine qualitative studies exploring maternal transition by Nelson (2003), who found that women were largely unprepared to deal with motherhood, and that the postpartum months were described as physically and mentally exhausting, and filled with uncertainty and emotional lability.

3.4 HIV and motherhood

The accumulation of environmental and emotional stress associated with being a MLWHA, can have wide-reaching systemic implications, and can interfere with responsive caregiving, the mother-child relationship, maternal mental health, and children's cognitive, emotional and social development (Stein, 2003). For example, Pregnant women diagnosed with HIV/AIDS might contend with a range of challenges including, their unpredictable infection, the specific consequences of some of the recommended MTCT prevention procedures, stigma, isolation, preparation for parenthood, potential relational difficulties, such as serodiscordancy (a couple in which only one partner is HIV-positive), blame, and abandonment (Gari, Habte, & Markos, 2010). These difficulties might be intensified by media images, which

overwhelmingly portray happy mothers, contented babies and helpful partners (Nicolson, 1998).

MLWHA may also experience uncertainty about transmitting HIV to their child (Santacroce, 2000). In addition, a qualitative study using interpretative phenomenological analysis (IPA) found that HIV-positive pregnant and postpartum women constantly worry about their infant becoming infected (Sawatphanit et al., 2004). Furthermore, mothers can also be fearful of infecting their children through casual contact, such as through hugging (Faithful, 1997).

Some of these assertions are supported by Sanders' (2008) phenomenological study, exploring the meaning of pregnancy after an HIV diagnosis, with nine New York-based women, aged 34-53. She found that their experience was characterized by distress, ambivalence, and stigma, alongside the need to rectify mistakes with existing children and be a better mother. This study highlights some of the women's contrasting experiences; however, the transferability is questionable due to the sample being self-selected with a focus on women with substance-use histories and child custody issues. It seems, Mercer's (2004) stages may be challenging for MLWHA, particularly forming a positive maternal identity, as they may consider themselves incapable, and fear being morally condemned as failure mothers (Beck, 2002b).

The importance of motherhood in the context of HIV is demonstrated by Doyal and Anderson's (2003) qualitative study with 62 African London-based WLWHA. They found that the majority of women highlighted childrearing, sexuality, and pregnancy as priorities, and as times when HIV particularly challenged their lives. However, motherhood was also deemed as an important source of their identity and legitimacy. Participants reported that their options were constrained by their own and

other's expectations of women's behaviours, and many had experienced at least one traumatic life-event, including rape, direct experience of HIV-related death, and the death of own child from AIDS. Doyal and Anderson's (2003) study captures how HIV is not always the primary disruptive issue, but is one of multiple difficulties (Bletzer, 2007). Furthermore, it demonstrates the importance of motherhood within these challenges, and points towards the importance of a holistic contextual framework when working with MLWHA. However, due to the purposive London-based sample, its generalisability is limited. Additionally, the methodology for the analysis used was not specified, compromising the rigour of the study.

Hebling and Hardy (2007) carried out a qualitative study using thematic analysis with 12 HIV-positive Brazilian women, exploring their feelings about motherhood, decision-making for their children's care, and identifying defence mechanisms used in dealing with their seropositivity. They found that motherhood was seen as an essential attribute and a reason for living and that some had made future care provisions for their children. However it emerged for these women that thinking about their children becoming orphans increased their feelings of impotence and guilt. Their defence mechanisms included compensation, denial, rationalisation, and projection. This study used a purposive, small Brazilian sample, and therefore the findings may not be applicable to a UK population. However, it illustrates some of the coping strategies used by MLWHA and highlights these women's and their children's needs for ongoing bio-psycho-social support.

Marcenko and Samost (1999) facilitated six focus groups with 40 American-based MLWHA. Several had histories of substance-abuse and 10 had HIV-positive children. Participants were primarily concerned with issues of disclosure and feelings

of guilt and anger about the lifestyle choices which had contributed to the contraction of HIV/AIDS. This study is useful in highlighting themes for clinical interventions; however, this sub-group may significantly vary from, for example, women with HIV-negative children. Important to mention is that issues around disclosure seemed a dominant theme in the majority of studies exploring the experience of being a MLWHA (See Murphy, 2008 for a more thorough review).

Furthermore, Sandelowski and Barroso (2003) carried out a meta-analysis of 56 American-based qualitative studies of motherhood in the context of HIV. They found two primary goals of MLWHA: (a) protecting children from HIV-related stigma and from contracting HIV, and (b) the preservation of a positive maternal identity.

Additional relevant findings included 1) mothers' struggling with whether to disclose their status to their children, and mothers' worrying about others' negative reactions to themselves and their children (Santacrose, Deatrck, & Ledlie, 2002; Ciambrone, 2002), 2) mothers concerns over child-care, especially if their disease worsened and/or after their death (Hackl, Somlai, Kelly & Kalichman, 1997), and that 3) motherhood seemed to be central to their identities, and brought positivity, strength, normalcy, inspiration and hope into their lives (Ciambrone, 2002, Goggin et al., 2001).

The findings' generalisability is limited as the samples were mostly American, small, self-selected, were aware of their HIV-status before pregnancy, and had used substances, leading to child-custody issues and MTCT in some cases. Additionally, the studies' findings were based on varying definitions of concepts, such as ethnicity and family, and were conducted in diverse contexts, making meaningful comparisons

challenging. Moreover, as reported by the authors, caution must be employed owing to subjectivity, as the syntheses of findings are based on the construction of the researchers' interpretations of the data, which are based on the participants' constructions of their experiences. Furthermore, the methodologies were not standardised, making replication difficult. However, the review offers a clinically rich insight into the experiences of motherhood in the context of HIV.

Similarly, other qualitative studies focusing on MLWHA mainly use an American sample, with the majority of participants having a substance-abuse history and choosing to become pregnant following diagnosis (Sanders, 2008; Stevens & Hildebrandt, 2006). Studies exploring the pregnancy decision-making following an HIV-diagnosis, found that women weighed concerns about their own health and vertical transmission, against their desire to have a child. Furthermore stigma, religious beliefs, and others attitudes played a role (Craft et al., 2007).

3.5 Additional considerations- negative discourses and stigma:

There is an increasing evidence-base highlighting the negative impact that HIV-related stigma and discrimination can have on the mental health of PLWHA (DeBruyn, 2002; Nyblade, 2003). More specifically, MLWHA are faced with the moral and sexual discourses of blame, perversity, and culpability (Bredstrom, 2006), and have been portrayed as helpless, dangerous, needing pity (Squire, 1993) and as "dirty, diseased and undeserving" (Lawless, Kippax, & Crawford, 1996, p. 1371). These images and conceptualisations may lead to a spoiled identity (Rohleder & Gibson, 2006), internalised stigma, and foster feelings of self-condemnation and guilt (Lawless et al., 1996). Similarly, Sontag (1988) suggested HIV/AIDS has replaced

cancer as the disease most demonised by society. She stated that societies need to have an illness which is identified with evil and attaches blame to its victims.

Therefore it has been suggested that being black, African, an asylum-seeker or refugee woman, a mother, and HIV-positive, can imply an intersection of marginalized, rivalling, oppressive and incongruous identities (Dodd et al., 2004) which can impact upon psychological well-being.

3.6 Summary:

MLWHA face multiple challenges, including stigma, discrimination, concerns about the children's wellbeing, preserving a positive maternal identity, disclosure decisions, and guilt. However, motherhood in the context of HIV has been repeatedly shown to be a source of strength and normalcy. Furthermore, African MLWHA may experience additional challenges such as traumas, socioeconomic difficulties, psychosocial issues, and cultural conflicts with MTCT prevention procedures.

4. MODELS AND MEDIATORS OF COPING WITH HIV

With an increased interest in MLWHA's QoL, it is important to consider mediators which might contribute or hinder this, and theories around coping. Owing to the lack of literature focusing specifically on motherhood and HIV, other relevant theories including the illness representation model, the social cognitive transition model, and family illness narratives will be drawn upon. This review acknowledges that there are multiple coping mediators at play for this population; however it is beyond the scope of this review to explore all, therefore two factors which were pertinent in the African MLWHA literature were around religion and spirituality, and social support, therefore these will be discussed further.

4.1 Adjustment

The Social-Cognitive transition model of adjustment (Power & Dalgleish, 1997) theorised that individual differences in responding to illness are reflected in three primary factors, 1) cognitive models of the self, world, and others, 2) social contexts through which events are experienced, and 3) the diversity of people's characteristic styles of responding to information incompatible with their assumptions.

Conversely, Taylor (1983) posited that the processes involved in adjusting to a threatening event included 1) causal attributions and reassessing goals and values, 2) gaining a sense of mastery, and 3) enhancing self-esteem. Gaining mastery might be particularly challenging for MLWHA owing to low self-esteem (Ross, Sawatphanit, Mizuna, & Takeo, 2011), and the unpredictability of HIV/AIDS may find gaining mastery difficult.

These models emphasise the usefulness of understanding one's social context and perceptions of diagnosis and how this can facilitate coping. This seems important as easing of psychological distress and processing of traumatic experiences has been linked to better immune function and longer survival in PLWHA (Golub et al., 2003). One way of thinking about people's illness perceptions is by using the illness representation model (IRM).

4.2 Illness representation model and family illness narratives

According to Lazarus and Folkman's (1984) theory, coping is the process of managing internal and external demands, which are appraised as taxing or exceeding the individual's resources. The IRM focuses on the relationships between illness

representations (IRs) and coping (See meta-analysis by Hagger & Orbell, 2003). IRs are distinct culturally-based, learnt patterns and interpretations of how individuals experience, explain and manage an illness (Radley, 1994).

Leventhal, Benyamini, and Brownlee (1997) described the five components of the IRM: 1) *Identity*: the label given to the condition and symptoms; 2) *Cause*: ideas about the perceived cause of the condition based upon information gathered from a variety of sources. 3) *Time-line*: the predictive belief about how long the condition might last; 4) *Consequences*: beliefs about the consequences and impact of the condition; and 5) *Curability/controllability*: beliefs about the treatability and control over the condition. This can be explored in terms of the individual's perceived locus of control (Rotter, 1954). Pincus and Morley (2001) propose that when the illness and self-schema become enmeshed, for example when people define themselves by negative aspects of the illness, the person may become depressed.

Hale, Treharne, and Kitas (2007) argue that the IRM is reductionist and neglects the role of and interaction with significant others and wider contexts. This limitation is of particular importance for African MLWHA, as describing psychological distress in the context of social and interpersonal situations may resonate better in traditional societies and minority communities in the West (Patel, 1995). Conversely, family illness narratives arguably incorporate the interpersonal and contextual influences of HIV/AIDS, and therefore may be useful when considering African MLWHA. Family illness narratives are the stories families tell about their illness experiences (Hardwick, 1989). As illness experiences accumulate and recur, they become family myths/legacies, including beliefs about who gets sick

and why, and what are appropriate ways of coping, caring, and communication (Bury, 2001).

4.3 Spirituality and religion

Research has indicated that individuals often turn to religion and spirituality when coping with change and difficulties (Dein & Stygall, 1997). Religion has been shown to have positive effects on coping, and provides a sense of inner-strength for people from Africa when dealing with HIV (Doyal & Anderson, 2005). Additionally, religion can contribute to one's attributions of the nature, controllability, and positive reframing of an illness (Pargament et al., 1990). It has been found that for PLWHA, spirituality can provide a sense of meaning when one's existence is threatened (Frankl, 1959; Jenkins, 1995).

Research has shown that PLWHA who report greater engagement in spiritual activities report lower emotional distress (Sowell et al., 2000), lower depression (Simoni & Ortiz, 2003), greater optimism (Biggar et al., 1999), better psychological adaptation (Simoni, 2002), and greater control of CD4 cells (Ironson, Stuetzle, & Fletcher, 2006). Furthermore, Chinouya and O'Keefe (2005) found that some UK-based Africans believe that prayer can cure HIV without medication, and that being religious can prevent HIV transmission.

Maman, Cathcart, Burkhardt, and Behets (2008) carried out interviews with 40 Congolese HIV-positive pregnant or new mothers about the role of religion in their lives. Women reported that religious leaders and spirituality were important sources of support. As acknowledged by the authors, this study demonstrates the support religion can play, however, as the study did not focus on spirituality it is difficult to conclude spirituality's influence. Additionally, information was not collected on the

women's religious affiliations; therefore, it was not possible to identify patterns in different religious beliefs.

The above indicates that one's religious and spiritual beliefs and practices can be adaptive ways of coping and managing with HIV, however also may compromise adherence to medical treatment.

4.4 Social support

Social support has been identified as one of the most important factors explaining differences in QoL following diagnosis (Felton & Revenson, 1984). MLWHA may experience stigma which can lead to self-imposed estrangement and decreased socialisation (Longo, Spross, & Locke, 1990). Social exclusion can threaten a sense of belonging, self-esteem, control, and meaningful existence (William & Govan, 2005).

Research has shown that support during pregnancy can reduce the likelihood of low-birth weight infants (Killingsworth Rini et al., 1999), increase self-confidence in the motherhood role (Oakley, 1979) and reduce the prevalence of depressive symptoms in the postpartum period (Beck, 2002).

Serovich, Kimberly, Mosack, and Lewis (2001) reported that support networks are crucial buffers against emotional distress in women. Research suggests that HIV/AIDS support groups can enhance self-efficacy, mastery, reduce social isolation, and emotional distress, (Simoni, 2005) foster greater disclosure, and increase knowledge of issues relating to HIV/AIDS (Gillett & Parr, 2010).

4.5 Cultural variations in illness models

This section will explore some cultural considerations which may be important when integrating the different coping models and mediators, with a particular view on their applicability to African MLWHA, as people's sense-making, pre-existing beliefs, and assumptions are believed to be influenced by cultural factors. Scandlyn (2000) suggested that how a society interprets and classifies symptoms, treatment, and assigns the sick role varies according to multiple factors, from geographic location to political economy. Similarly, Kleinman (1988) stated that conceptualisations and management of experiences are culturally shaped, as individuals have learned to think and act within their social context. Therefore, when developing interventions in a diverse society, it is important to consider alternative ways of making sense of illness.

This seems even more pertinent when applying some of the previously discussed factors to people from various ethnic minority backgrounds. For example, those from different cultural backgrounds may have varying illness representations (Leventhal et al., 2001), such as, seeing the self, identity, and body as inextricably linked (Coker, 2004). Furthermore, Karasz (2004) explored cultural differences in conceptual models of depression by presenting two cultural groups in New York: South Asian immigrants (SA) and European Americans (EA) with a vignette describing symptoms of depression. Results indicated pervasive differences in representational models across the groups. SA participants identified the "problem" in social and moral terms, and emphasized self-management and lay referral strategies. This study is useful in highlighting some of the potential differences among cultural groups in illness explanations and treatment choices, however, caution must be used when interpreting these findings, as the sample was small and the views expressed

were not contextualised within other important factors, such as length of stay in country and educational level.

These differing illness explanations extend to people's perception of HIV, its cause, meaning, and consequences. Therefore the following studies demonstrate some of the discourses associated with HIV/AIDS, with the aim of further understanding some factors which might shape African MLWHA experiences.

Studies carried out in Zimbabwe, Tanzania, Uganda, and South Africa found that HIV/AIDS was conceptualized as a social and physical death. This increased people's feelings of distress, helplessness, and fostered denial and secrecy (Meursing & Sibindi, 2000; Ankrah, 1992; Dautzenberg, 1992; Coleman, 1996).

Koku (2010) discussed how discourses around HIV as death are evident in linguistic labels such as *maiti inayotembea* (walking corpse) used in Tanzania and *makizi yaku mochari* (keys to the mortuary) used in Zambia (Mill, 2001; Nyblade et al. 2003). Some of these discourses might have been influenced by negative experiences of HIV in Africa, where medical care is limited (Yandell, 2006), knowledge is generally poor, and mortality rates are high (Monasch & Mahy, 2006).

In many countries, HIV is believed to result from deviant, social, and religiously proscribed behaviours, such as extramarital sexual relations, promiscuity, homosexuality, prostitution or sexual relations with foreigners (Mill, 2001; Ulasi et al., 2009), or linked to sorcery and witchcraft (Strickland, 2004), or as a punishment for sin (Parker & Aggleton, 2002; Okpako, 2006).

4.6 Summary:

These studies capture multiple explanations for HIV/AIDS, which are useful when considering clinical interventions. However, they rely on self-report measures and observations, therefore increasing the likelihood of interpreter and social desirability bias. These studies also highlight the importance of considering one's social support system, and exploring one's conceptualisations and cognitions around illness, which may vary depending on one's cultural, political, social, religious, and family context.

5. CONCLUSION AND FUTURE DIRECTIONS

Given the increasingly high proportion of African MLWHA in the UK (Flowers et al., 2006) and the DoH and NHS's focus on delivering race equality and cultural competence, (DoH, 2005; Race relations Act, 2000), it is surprising that there is a dearth of literature exploring their needs and experiences. The majority of research avenues on MLWHA have focused on drug-using women and American samples (Onwumere, Holtum, & Hirst, 2002; Rohleder & Gibson, 2006). Furthermore studies have tended to be behavioural and biomedical focused, predominately exploring issues around disclosure (Letteney & LaPorte, 2004), child care plans/provisions (Jones, 2004), and on an HIV-positive woman's decision to become pregnant (Bedimo-Rung et al., 2005), thus neglecting the relational and psychosocial lived experience of African MLWHA in the UK.

Furthermore, most studies focus on the challenges which face MLWHA, as opposed to exploring their resilience and strengths. Moreover, few studies have specifically examined motherhood in the context of maternal illness (Radtke & Van Mens-Verhulst, 2001). In addition, IRs, appraisals, and family narratives around

illness, can be influenced by numerous factors, including one's contextual and cultural influences and beliefs, the media, health-care messages, and medication availability. Therefore, continuous exploration is needed to meet these dynamic needs.

Moreover, there is a dearth of research distinguishing between the varying needs faced by different sub-groups of MLWHA, for example those whom have HIV-positive children, and/or are asylum-seeker and refugee women.

This review concludes that African MLWHA are faced with a complex plethora of experiences, including difficulties around some of the MTCT prevention measures, experiences of stigma, guilt, previous trauma and losses, disclosure decisions, emotional distress, and concern over children's welfare. Taking into account the increasing HIV prevalence rates amongst mothers within the British context, HIV being re-defined as a chronic illness, African MLWHA's unique challenges, and the potential impact on children born to MLWHA, more research is needed on their and their children's QoL issues and experiences to inform suitable life-enhancing interventions.

Therefore this review indicates that the following future research avenues would contribute to enhancing the evidence-base and understanding of African MLWHA:

1. Understanding experiences of UK-based African women diagnosed with HIV during their pregnancy.
2. The inter-relationship between African MLWHA's illness representations and their coping strategies.
3. The impact of an HIV-diagnosis on the mother-child relationship.

4. A comparison of the experiences of being a UK-based African MLWHA and refugee/asylum-seeker compared with a comparison group.
5. A longitudinal exploration of UK-based African MLWHA at different illness stages.

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SECTION B: EMPIRICAL PAPER

The meaning and experience for UK-based African women after being diagnosed with HIV during their pregnancy, and their subsequent coping strategies.

Word Count- 7986

Word Count with abstract and references- 10,107

Abstract

A qualitative investigation was conducted to explore the experience of African women living in the UK after being diagnosed with HIV during their pregnancy. Twelve participants completed a short demographic question, and participated in a one-to-one semi-structured interview. The interview was designed to address multiple personal, interpersonal, and systemic issues related to their HIV status, and HIV in the context of motherhood. Data were analysed using interpretative phenomenological analysis (IPA). Themes which emerged included: HIV being part of one's wider tapestry, community and systemic influences and responses to HIV, experiencing a different story of HIV, and the mother-child relationship. Strikingly, the aspect of HIV that these women reported finding most distressing was their inability to breastfeed, which seemed central to their cultural identity as mothers. While the generalisability of these findings is clearly limited, nevertheless it seems important for clinicians to (i) recognise that HIV may not always be the primary difficulty facing their clients, and may be amongst numerous other factors, (ii) consider systemic and contextual factors, including cultural influences and past trauma, (iii) focus on client resources and capacity for resilience, and (iv) support clients to access local resources, including support groups, (v) attend to issues around confidentiality, disclosure decisions and breastfeeding, and (vi) hold in mind the potentially powerful and helpful affect for these women of witnessing different narratives around HIV. The continuing need to counteract stigma and discrimination, including from health professionals and from the media, was also apparent.

Key words: African, maternal HIV, refugee, asylum-seeking, pregnancy

1. Introduction:

In 1999, the UK introduced an opt-out antenatal testing policy resulting in many new HIV diagnoses being detected during pregnancy. Motherhood requires constant change, redefinitions of self, relationships, and goals (Sethi, 1995). Pregnant HIV-positive women have additional challenges to cope with, which can be understood using Mercer's (2004) stage model. These mothers not only have to move towards a new normality and achieve a maternal identity, which may be influenced in the context of newly diagnosed HIV. In addition they may also experience personal, social, and biological transitions (Smith et al., 2009), and contend with uncertainty and fear about transmitting HIV to their child (Santacroce, 2000), unpredictable infection, stigma, isolation, relational difficulties, such as serodiscordancy (a couple in which only one partner is HIV-positive), abandonment, blame, and loss of economic support (Gari, Habte & Markos, 2010).

With these challenges in mind, several theoretical models point towards the importance of considering and understanding individual differences in sense-making, coping, and managing HIV. It is important to consider individual's influences and beliefs, particularly as people from different cultural backgrounds may have varying illness scripts/narratives (Kleinman, 1988; Hardwick, 1989) and illness representations (IRs) (Leventhal et al., 2001). In the Illness Representations Model, (Leventhal, Nerenz, & Steele, 1984), IRs are culturally-based, learnt patterns, and interpretations of how an individual experiences, explains, and manages an illness (Radley, 1994). It uses five illness perceptions to explain this: 1) *Illness identity*- illness symptoms and label, 2) *Timeline*- perceived length of illness, 3)

Consequences-perceived severity and the social, physical, and psychological consequences of the illness; 4) *Causes*- beliefs about what caused the illness, and 5) *Controllability*-perceptions of whether the illness can be controlled or cured. For example, Mothers living with HIV/AIDS (MLWHA) are often the primary caregivers in a family constellation (Bor & duPlessis, 1997), and may experience guilt about the impact of HIV on their family (Goggin et al., 2001). The accumulation of environmental and emotional stress can lead to high levels of distress and depression (Murphy et al., 2002) which can interfere with effective parenting, maternal wellbeing, the mother-child relationship, and the child's cognitive, emotional, and social development (Stein, 2003).

To date, most research on MLWHA has focused on drug-using women, American samples (Onwumere, Holtum, & Hirst, 2002), and concentrated on behavioural, risk, and biomedical aspects. Studies have predominately explored disclosure issues (Letteney & LaPorte, 2004), childcare provisions (Jones, 2004), and an HIV-positive women's reproductive decisions (Bedimo-Rung et al., 2005). Few studies have examined motherhood in the context of maternal illness (Radtke & Van Mens-Verhulst, 2001) or considered the relationship between illness and identity in the context of HIV. Additionally, most studies have focused on problem-saturated discourses, as opposed to exploring this population's capacity for resilience.

Another underrepresented group in the literature is people of African origin, despite the evidence that in the UK they are the second largest identifiable group of HIV-positive service-users in the NHS (Kesby, Fenton, Boyle, & Power, 2003). Although the term "African" will be used, it is acknowledged that this implies homogeneity, within a heterogeneous group of individuals comprising of numerous cultures, languages, tribes, religions, nationalities, and ethnicities (Elam et al., 1999).

This population may include asylum-seeking or refugee people whose needs are multi-dimensional (Papadopoulos, 2001). They may have to justify their presence, whilst living in legal limbo (Luebben, 2003) and under the omnipresent threat of being repatriated (Sourander, 2003), whilst contending with a myriad of psychosocial difficulties, including language barriers, housing, and unemployment (Ibrahim, Anderson, Bukutu, & Elford, 2008). Moreover, many have experienced traumas, losses and political uncertainty. Forsyth, Burns and French (2005) found that UK presentation patterns of HIV correlated with periods of conflict and political unrest in one's country of origin. For example, the female HIV-prevalence in Rwanda prior to the 1994 conflict was 1%, which rose to 11% by 1997, when an estimated 3% of all Rwandan women had been raped (UNAIDS/ WHO, 2003).

Within this population, some mother-to-child-transmission (MTCT) prevention procedures may instigate questions about how these measures conflict with cultural practices and norms (De-Sammy, 2006). In the extant literature, a particular challenge for HIV-positive African mothers has been the requirement to not breastfeed (Doherty et al., 2006; Kebaabetswe, 2007).

For some, HIV is coupled with deviant, social, and religiously proscribed behaviours, such as promiscuity, homosexuality, prostitution and sexual relations with foreigners (Mill, 2001; Ulas et al., 2009), or as a result of punishment, sorcery, or witchcraft (Parker & Aggleton, 2002; Okpako, 2006). Moreover, HIV has been strongly associated with death and dying, as Koku (2010) illustrated in his discussion of linguistic labels for HIV in various African countries, such as *maiti inayotembea* (walking corpse) used in Tanzania; *makizi yaku mochari* (keys to the mortuary) used in Zambia; and *menfese mute* (ghost) used in Ethiopia (Mill, 2001; Nyblade et al., 2003).

These complexities indicate that being an asylum-seeking/refugee MLWHA can imply an intersection of marginalized, stigmatised, rivalling, and oppressive identities (Dodd et al., 2004). Given the increasingly high proportion of African MLWHA in the UK (Flowers et al., 2006) and the Department of Health (DoH) and NHS's focus on delivering cultural competence (DoH, 2005), it is surprising that there is a dearth of literature exploring their needs and experiences.

Taking into account the re-conceptualisation of HIV as a chronic illness (Clarke, 1994), the availability of medication in the UK, and associated increased life expectancy, more consideration is required to explore these women's quality of life (QoL) issues, coping styles, and lived experience. Whilst deductive quantitative approaches may be useful in the future, the existing literature neglects the relational and psychosocial lived experience of African mothers in the UK, who are often refugee or asylum-seeking women diagnosed with HIV during their pregnancy. Their complex plethora of experiences is indicative of the need for a more in-depth qualitative exploration, owing to the significance of maternal wellbeing on child outcomes, the mother-child relationship, and early intervention opportunities.

2. Aims:

This study uses a qualitative approach to explore the following research question, "What are the experiences and how do UK-based African women perceive, make sense, and manage a diagnosis of HIV during their pregnancy, and subsequently?"

This study hopes to extend current understanding on how best to support this population, both at the time of diagnosis and subsequently, and to inform useful life-enhancing psychological models.

3. Method:

3.1 Recruitment:

All participants had or were attending a London-based antenatal group for African women who had been diagnosed with HIV during their pregnancy. This group was held monthly at a church and run by a local charity. The majority of the women had intermittent contact with the group facilitators. The researcher presented the research to the charity team, and subsequently was invited to attend the group. The majority of participants were recruited through this group, and the remaining sample, who tended to be former or less frequent group members, were contacted via the group facilitators. Prospective participants received an information sheet (Appendix 2) and those who consented were contacted via telephone and were introduced to the project, offered the opportunity for questions and sent the consent form (Appendix 3). Once they consented, participants were invited for an interview.

3.2 Site

The interviews took place at the London charity base in a small private room.

3.3 Participants:

The purposive sample included 12 participants. Interpretative Phenomenological Analysis (IPA) uses small, purposively selected and carefully situated samples (Smith et al., 2009). In keeping with IPA's notion of having a homogenous sample, the following inclusion criteria were met: all participant's were: 1) female, 2) self-identified as African, 3) over 18-years old, 4) living in the London vicinity, 5) had or were attending an HIV-antenatal group, 6) diagnosed with HIV during their pregnancy, 7) able to communicate verbally in English, and 8) willing to participate. Participants who did not meet these criteria were not approached and therefore were excluded.

The participants were aged between 23-41, with a mean age of 32. Their length in the UK ranged from 2 to 19 years, with a mean of 8 years. Time since diagnosis ranged from 10 months to 7 years, with a mean of 5.2 years. They had a range of employment and marital statuses, educational qualifications, and were from a variety of religious and cultural backgrounds. Countries of origin included Rwanda, Uganda, the Congo, Sudan, Ivory Coast, Zimbabwe, Nigeria, and Ethiopia. Immigration status varied, however the majority were asylum-seeking women. For further demographic details See Appendix 6, however to preserve anonymity these will be removed and/or modified before binding.

3.4 Ethical considerations

The study was reviewed by a university ethics panel (See Appendix 17) and adhered to the BPS code of ethics and conduct, and DCP professional practice guidelines (DCP, 1995; BPS, 2006). Participants received information sheets

detailing information on confidentiality and its limits. Prior to agreeing to take part, these were discussed, and re-emphasised at the interview. Participants signed consent forms and their right to withdraw or opt-out at anytime was made clear. To accommodate for any distress, the researcher's clinical skills were utilised and participants were supported by the charity and a specialist HIV-service. Furthermore a list of supportive organisations was distributed (not included to ensure confidentiality).

3.5 Design

This study used a non-experimental, qualitative design. The information was collected using semi-structured interviews.

3.6 Data collection and interview schedule:

The interview schedule was formed from the extant literature, and through consultation with field experts, and the group facilitators. Subsequently two pilot interviews were carried out with women who matched the inclusion criteria. Participants were asked to comment on the style, language, and content of the interview. Feedback was positive and the questions and style were found to be suitable and adequately addressing the research topic, therefore it was not felt necessary to make any significant changes.

The questions were broad to allow participants to focus on what was salient to them, and included questions around what HIV meant to them, their diagnosis experience, and coping strategies (See Appendix 4 for the interview schedule). The interviews were recorded and lasted between 40 to 90 minutes.

3.7 Analytic strategy:

This exploratory study sought to understand complex phenomena (Camic, Rhodes, & Yardley, 2003) therefore IPA was chosen, as it was felt it best captured the multiple meanings which participants ascribed to their experiences. It also highlights the significance of the social and cultural context, and acknowledges the centrality of meaning and the co-construction of the research endeavour. IPA aims to understand the perspective of particular people, in a particular context. Its idiographic slant allows the reader to appreciate the phenomenon at the level of the individual, and the wider group of participants.

The interviews were transcribed verbatim and analysed using the guidelines for conducting IPA outlined by Smith (2004, 2009):

- 1) Themes were identified and labelled through repeated reading.
- 2) Connections were recorded between emerging themes.
- 3) A master of themes and sub-themes was compiled.
- 4) The above stages were repeated for each transcript.

3.8 Quality assurance:

The research supervisor conducted an independent audit process on 3 transcripts to ensure themes and sub-themes were not overrepresented and had cross-transcript reliability.

Furthermore, illustration quotations and grounding examples from interview data were used to evidence participant's voices in the interpretations made (Smith et

al., 2009), with the aim of allowing readers to assess the persuasiveness of the analysis for themselves.

Moreover, participant information was gathered to situate the sample further by establishing some key contextual factors (Appendix 7). Furthermore, respondent validation (Appendix 17) was collected in order to determine whether the emerging themes were representative of the participant's interviews.

Additionally the researcher was reflexive and recorded her assumptions and hypotheses (Fischer, 2009) in a research diary (Appendix 14). Some of the assumptions, experiences, beliefs, and values which the researcher feels most likely influenced the research, include that the researcher is a white, middle class, female, and has been trained as a clinical psychologist. The researcher has a particular interest in narrative therapy, resiliency, trauma, loss, and attachment. The researcher also has South African parents, and has spent a considerable amount of her life living, working, and travelling in different parts of Africa. The researcher also has worked with both individuals and communities affected and infected with HIV/AIDS. Arguably, these experiences impacted on the researcher's ability to access, engage, and connect with the study's participants. These experiences also would have impacted on how the researcher analysed and interpreted the data, and it is acknowledged that other researcher's may have given prominence to other facets.

3.9 Procedure

Participants were given time to ask questions and their understanding of the study was checked. Participants were informed that all personal identifying information would be removed from written transcripts and any quotes would be sufficiently anonymised.

While conceptual interest areas guided the interviews, participants were accorded the status of “experiential expert” (Smith & Osborn, 2003) and encouraged to recount their stories with minimal interruption. Following the end of the interview, participants completed a demographic questionnaire. Participants had the opportunity to feedback on their experience and provide their details should they wish to receive the findings.

4. Results:

Analysis of the data highlighted the emergence of 4 super-ordinate themes and 18 sub-themes, which describe the meaning and experience for these UK-based African women after being diagnosed with HIV during their pregnancy. These are detailed in Table 2, and will be explored and illustrated with verbatim extracts.

To ensure confidentiality, participants have been given pseudonyms and all identifying information has been removed. Where material has been omitted, blank square brackets are used [].

Table 2: Summary of the master, sub-themes and occurrence of themes arising from the participants' accounts.

Master theme	Sub-theme	Occurrence of theme (number of participants for whom the theme occurred)
HIV as part of a wider tapestry	Emotional responses to the diagnosis of HIV	12
	Traumatic experiences	7
	Psychosocial stressors	11
	Educational experiences	4
Community and systemic influences and responses to HIV	Significant relationships	12
	Social support	12
	The role of health professionals	11
	Media influence	5
	HIV-related discourses	12
Experiencing a different story of HIV	Being accepted and embraced	8
	Healthy lifestyle	6
	Expert of experience	7
	HIV can touch all	6
	HIV as not the master identity	7
Mother-child relationship	Child as protective factor	11
	Fear for child's health and future	11
	The complexity of not breastfeeding	12
	Pregnancy as a mixed experience	6

4.1 HIV as part of a wider tapestry

This master-theme indicates that for the majority of women, HIV was experienced as one part of their wider tapestry, within the context of multiple other threads, including traumas, psychosocial stressors, educational experiences, and religion.

Before considering the above factors, it seems important to reflect on some of the initial emotional responses experienced at the time of diagnosis, which seem to illustrate the HIV thread within the broader fabric of one's life.

4.1.2 Emotional responses to the diagnosis of HIV

Several participants expressed feelings of shock, fear, paranoia, hopelessness, disbelief, self-neglect, of contemplating suicide, and expecting to die imminently. Some women reported responses characteristic of freezing and dissociating; they seemed to separate from the information they were receiving. The diagnosis seemed to challenge the women's homeostasis in different ways.

Camille: *I was numb; it was like I was watching it happen to someone else.*

Bebi: *I was so shocked; I didn't think it was true, so I got tested lots more times..*

Grace: *I wanted to commit suicide. I didn't care about myself, I starting giving things away; I was preparing myself to die.*

Najah: *I was paranoid, hearing things, and talking to myself.*

Other responses were around questioning one's own susceptibility and vulnerability to HIV. This seemed particularly flavoured by one's previous beliefs about the type of person who contracts HIV.

Batu: *I thought HIV only happens to certain people, those who are bad and sleep around, not me!*

4.1.3 Traumatic experiences

This sub-theme illustrates how several women's tapestry were woven and interlinked with experiences of loss and trauma, including family members being murdered or themselves being kidnapped and/or abused. In some cases these violations had led to the contraction of HIV and/or their pregnancy being a product of rape.

Grace: *People were killed; I survived, because they thought I was dead, you can see the scars on my face, where the bullets entered my face. They did what they wanted with us, beating us, having rape parties, that's where I got HIV from, so there's more to this HIV.*

This depicts some of the challenges, in addition to HIV, which these women have faced. It seemed important for some of the women to share their wider story, which captured their context and journey behind and/or before HIV. For example, the above extract was in response to the researcher asking about Grace's diagnosis experience. This illustrates how HIV seemed to be shaped, and embedded with other trauma experiences, and subsequently interlinked with one's conceptualisations of HIV.

4.1.4 Psychosocial stressors

The majority of women were contending with multiple psychosocial stressors, which in many cases, as opposed to the HIV, appeared to be at the forefront of their concerns. Some women made a direct link between their worsening of their health

and various psychosocial stressors. For others, HIV represented wider political and economic issues, such as poverty.

Grace: my son is being deported, I'm so stressed, it's affected my health!

Camille: I can't work because of my status and I live in an awful place; there's no room for my child to play.

Najah: all I wanted was to study at school, but I couldn't afford it, so I had to be with 3 different men to help fund me, so poverty causes HIV.

4.1.5 Educational experiences

Some women spoke of how their experience, exposure and knowledge of HIV had been protective, and enabled them to feel more hopeful and informed.

Shona: I never thought I'd die, because back home I [] volunteered on an anti-HIV campaign, and they taught us the positive aspects of HIV, and the incorrect HIV myths.

4.2 Community and systemic influences and responses to HIV

This master-theme addresses how relational aspects were at the forefront of these women's experiences, protective factors, and/or concerns in the context of HIV. Furthermore perceived or actual stigma/discrimination seemed to colour all aspects of living with HIV, including that from broader influences, such as within health systems and the media arena.

4.2.1 *Significant relationships*

This theme captures the centrality of relationships to these women, and the convolutedness which occurs around engaging in sexual relationships, and/or disclosure decisions.

Most notably, how, who, if, and when to disclose seemed to dominate the women's questions. These decisions seemed to be influenced by the women anticipating negative responses. Disclosure felt particularly challenging when in reference to significant people, however this concern extended to others in the community.

Shona: I haven't told anyone [] back home they think of me very highly, it's better our relationship stays good.

Kabira: [] I'm always scared, debating what will happen if I say it. [] It's a burden, a secret [].

Mary: I don't know how to find the words, or if they will be accepting or rejecting, but I think rejecting. [] I feel like it's written on my head.

These extracts highlight the complexity of disclosure, and capture a sense of HIV weighing-down on these women. HIV seems positioned as fuel for rejection and/or danger, and therefore lends itself to a world of secrecy, and reinforces a conspiracy of silence surrounding HIV (Danieli, 1984). The uncertainty of people's reactions seems overwhelming and restraining. Some women felt they would be seen negatively, or in a lesser way, which suggests that the threat to identity which HIV

poses is a major concern. The quote around HIV being written on Mary's head implies a sense of psychological imprisonment and of being eternally branded.

Responses to sharing one's status to a loved one seemed to include disbelief, avoidance, fear, blame, abandonment, and rejection. Additionally, some women faced the challenge of serodiscordancy, partner's suggesting termination, or learning that partners withheld their HIV-status from them.

Kabira: I told him (partner) to go and get tested but he refused and then he left us. He's in denial.

Grace: Mummy, are you going to die?

Nonetheless some women described those who had responded positively with warmth and unconditional support.

Bebi: My husband has been so so so wonderful and supportive.

Furthermore, some women discussed how HIV had restricted or changed their sex life. This illustrated the challenges to their femininity and sexual identity. Moreover, there seemed to be a sense of entrapment, and loss of freedom to engage in certain types of relationships.

Bebi: Sometimes it's difficult because we have to be careful and I want to protect and keep him healthy, so always using a condom can feel like a punishment and prison.

Kabira: If I met someone what do I say? Will they accept me? It's unwomanly!

4.2.2 Social support

This theme captures the support the majority of women felt from attending support groups. The support groups were reported as being an opportunity to share a common experience, to connect, be inspired, accepted, and unguarded.

Kabira: *I could be open and relaxed, take a breath, no one is there to judge, they're just like me. We learn alot from eachother and give eachother courage.*

Conversely, one woman shared how groups can act as a reminder of being HIV-positive, and where one can be faced with people in worse situations than themselves.

La-Tosha: *I don't go anymore because I don't want to see sick people or talk about HIV.*

4.2.3 The role of health professionals

The picture presented of health professionals varied significantly; there were several accounts of actual and perceived experiences of stigma, as well as breaches or disregards for one's confidentiality. However, health professionals seemed key in the majority of women's stories.

Camille: *I heard the doctor's secretary say to the other one, she's HIV-positive, and I thought everyone can hear!*

Kabira: *the GP looked at my book and said what's this? I said I'm HIV-positive and she shouted don't come back here again! That was the worst ever experience! I've never been back to any GP!*

Halina: *the midwives treated me differently; they threw my sheets away, put masks on, and only let me use certain showers. They didn't play with my baby like the others!*

The above extracts illustrate the threat associated with HIV, and the actual and/or perceived discrimination experienced. In many cases these responses seemed more influential as they were from people in positions of authority and/or knowledge.

These responses seemed to impact on the women's self-perceptions and relationship to help.

For most, a concern seemed to be having agency over disclosure decisions, and the fear of one's status being revealed without their consent, therefore emphasising the importance of confidentiality. This significance seemed to extend to other aspects of the community.

Grace: It was awful; a trainee doctor broke the news in front of someone from my country!

Mary: People might see the hospital letters in my post-box.

Kabira: The staff were very professional, there was a time when my daughter needed medicine but I had visitors, so they waited for everyone to go. They didn't want to give her the medicine in front of everyone in case I didn't want people to know or ask questions, I felt so relieved and happy they thought about that.

Some women discussed the compassion and empathy offered by health professionals, and seemed to regard the team as significant in supporting them. There seemed to be a sense of the importance of professionals creating a space where the women could feel known, held, respected, treated with dignity, and where hope and future possibilities could be fostered.

Josephine: The consultant is very nice and supportive []. He doesn't rush you; he does his job wholeheartedly, he takes time to get to know you. They're helping me have another baby.

4.2.4 Media influence

The majority of women discussed the media's power, and commented on their hope that its messages could be transformative. Some women commented on times when HIV had been depicted in a true or different way, and how significant this had felt. Some women felt the absence or negative representation of HIV in the media further exacerbated fear, stigma, and disclosure concerns, whilst reinforcing discourses around HIV being too fearful or hopeless to be addressed.

Halina: there was a program about living healthily with HIV, I felt overjoyed, and wished everyone could watch, to know that HIV isn't just death and disaster.

Najah: I was watching Jeremy Kyle and there was an HIV-positive white woman and she told her husband and he hugged her and said he loved her. That was the first time I saw HIV on the TV especially on a white woman, it was special.

4.2.5 HIV-related discourses

Different discourses seemed central in understanding how people perceived and responded to HIV. These narratives seemed to be embedded within the women's cultural, religious, social, and political context.

Shona: They believe in witchcraft, fetish things, someone is cursing you. My sister believes someone sent it to me out of wickedness.

Bebi: I believe HIV is my destiny and G-d planned it.

The above extracts offer beliefs around HIV being a punishment/sin, curse and communication from G-d. This seemed to colour how some of these women made sense of HIV, and influenced one's coping styles. For example, for those who felt

religion played a role in managing and/or contracting HIV, prayer and engagement in religious activities seemed to feature significantly in their lives.

Grace: *I'm a strong believer. I pray everyday to make me better []*

Furthermore, most women highlighted the powerful sexual, condemning, and moral discourses associated with HIV.

Mary: *In my country HIV means you are dirty, you sleep around, you're immoral. You're a prostitute.*

Grace: *My mother died of HIV, my father died of HIV, my sisters of HIV, my brother of HIV, we were 7 and now are 2[].*

Esther: *HIV meant death, coffins, pointless!*

Halina: *I thought I'm going to die, in 2 months I'll be gone. That's the African mentality, you will be thin as a finger, and it will eat away at you [].*

The above extracts highlight the women's experiences, images, and references of HIV in Africa, and how these are triggered when one hears the word HIV. This also demonstrates the fear and assumption that one will have a suffering death. These are further reinforced by some of the women's direct experience of multiple AIDS-related deaths.

4.3 Experiencing a different story of HIV

This master-theme addresses the power of witnessing/experiencing a different story of HIV, which can challenge beliefs and assumptions, and offer new perspectives and possibilities. This included hearing the stories of healthy women diagnosed years earlier, and of less represented stories, such as white women or professionals with HIV. These experiences seemed to thicken some of the women's

HIV narratives, and allow them and in some cases, others, to see HIV and themselves in a different light.

4.3.1 Being accepted and embraced

Many women expected or had experienced responses of disgust, rejection, or abandonment, so when people responded in an accepting way, most found this important in the way they related to others and viewed themselves. Having people who held hope, maintained their previous way of relating, had knowledge of HIV, and sustained a physical connection to them seemed strengthening.

Grace: He (uncle) made me stronger, he said don't worry, people here live well, they get medication, and have children. He put into my mind that I'd live. He wanted us to share a drink and I said no you'll be HIV and he said no I'll be ok.

Kabira: My sister hasn't treated me differently, [] she hugs and kisses me.

4.3.2 Healthy lifestyle

This theme captures the multi-factorial experience of health, and highlights how seeing other women at different stages, who appear healthy and happy can be inspiring and engendering of hope. These women seemed to represent living proof that HIV meant more than death, with multiple encounters of this kind, these new perspectives were built-on.

Some women seemed to place great emphasis on being physically healthy, maintaining a desirable self-image, and valued others being unable to identify them as a “sick person”.

Furthermore, the availability of medication seemed to paint a different picture to the women's experience of HIV in Africa. For most, time seemed to contribute to

one's changing beliefs, as the more time they lived healthily, the more they were able to hold onto hope for an opportunity-filled future.

Grace: I love that no one believes I'm HIV-positive cos I look so good.

Mary: I eat healthily. I do lots of walking, [] and it really helps. It's much better here because meds are available.

Grace: she has had HIV for almost 18-years and has healthy children, and she said can you tell? I said no, the more and more I meet women like her I have hope.

4.3.3 Expert of experience

This theme illustrates how some women found ways to use their experience of HIV to support others, or take more active roles in their condition. Six women found being advocates and experts of experience beneficial, they reported feeling valued and having a unique perspective to offer. Several commented on how previously they would not have considered these sorts of endeavours, but having HIV had increased their empathy and provided them with a sense of purpose.

Grace: I tell others my story, how healthy I am, and I went on a course about choosing medication.

Josephine: before I thought silly HIV people, but now I know more so I must help them see that.

Halina: My degree is about empowering communities; I want to help people like me.

However, some women reported feeling unable to support others as they were still in the process of making sense of HIV.

Camille: *I would like too, but I don't think I would be much good to others as I'm still trying to accept it myself.*

4.3.4 HIV can touch all

The experiences illustrated below seemed significant in challenging and/or shifting some of the women's beliefs that HIV only happened to certain types of people.

Grace: *a doctor said I'm HIV-positive, can you believe it? Wow even a doctor?*

Halina: *This white woman came to counsel me and told me everything will be ok, people live a long time with medication. I thought she was lying, I didn't believe her, but then she told me she was HIV-positive and her and her children were living healthily, that was a big moment!*

4.3.5 HIV as not the master identity

Some women discussed how HIV had become part of their lives, but not the dominating theme. For some, HIV seemed to have been embodied and represented one thread of their identity, which had been integrated and woven with other aspects. However there was a sense that if they thought too much about HIV, they would feel overwhelmed; it would be as if HIV had won and was taking over and having too greater impact on their lives.

Halina: *I try not to think too much of HIV or my mind will go faraway.*

Grace: *HIV is part of my life and I'll take my medication as being my best friend.*

Camille: *You accept it as part of you, but not all of you, like a piece of clothes, and then you get on with it.*

4. Mother-child relationship

This master-theme encapsulates motherhood as central to these women's lives, and captures how HIV influenced the mother-child relationship.

4.4.1 Child as protective factor

In the majority of cases, the child was seen as a saviour and driving force in their mother's lives. For some, their child gave them focus, motivation to live, and was positioned as the reason for an early diagnosis.

Kabira: Having her has made me better; she gives me a reason to live. I just want the best for her, I hardly think of myself.

Josephine: it's made us closer [] It's made me see her as even more precious.

Halina: I loved her more because I thought without her I wouldn't have known about HIV and G-d wanted me to know.

4.4.2 Fear for child's health and future

A primary concern for the majority of mother's was their children's health both through MTCT routes, and through subsequent contact. For some women, despite their children being HIV-negative, the fear of transmitting HIV through other forms of contact remained.

Kabira: I didn't ask about anything to do with me, my main concern, 100% was my daughter, for her to be healthy and not infected.

La-Tosha: I wanted to have an abortion as it wasn't fair if she (baby) was sick.

Bebi: I was worried to touch my son, feed him or sleep with him, it took me a long time, and even now if I cut myself I throw the knife away, I'm always cleaning!

One woman shared about how her partner feared that she would transmit/contaminate HIV to their child, and in doing so she reported feeling watched, judged, and unsafe.

Mary: *He keeps an eye on me, when I have my period, or the way I play, kiss her, give her a bath or change her nappy, he is scared I might pass it to her.*

Furthermore several women discussed their fear of what provisions would be put in place to look after their children after their death.

Kabira: *I think will I go to an age when I will see her grow? If I pass away what will happen to her? It's too much to bear.*

4.4.3 The complexity of not breastfeeding

All of the women reported feeling that not breastfeeding was particularly challenging. Some women felt this changed the mother-child connection, aroused suspicion from others about why they were not breastfeeding, felt unnatural, and not womanly. Several women pointed out the cultural importance of breastfeeding in Africa. The following extracts demonstrate some of the emotional, cultural, and moral dilemmas faced by women not breastfeeding.

Shona: *Everyone was asking why aren't you breastfeeding? I kept on defending myself with different excuses. It hurt me so much, even if no solution to HIV, a solution to breastfeeding would be so important, []for African women it's not normal. My baby cried so much and usually if you give them a breast they will stop but I couldn't, you feel selfish. I thank g-d I didn't have him in Africa!*

Batu: *I felt I was missing out. It was difficult; it felt less close and womanly.*

4.4.4 Pregnancy as mixed experience

The following extract shows how some women experienced a bitter-sweet pregnancy, and felt that receiving an HIV diagnosis had ruptured and/or challenged the normalcy and joy of becoming a mother. In some cases the pregnancy was interwoven with traumatic experiences.

Mary: *it was different. With my son I felt all the excitement, I couldn't wait to hold him, but with her I'm terrified what might happen to her and am always worrying []*.

Grace: *I don't know who their father is, a rapist though.*

4.4.5 Capacity for resilience

It feels important to acknowledge the capacity of resilience which emerged in the majority of the woman's stories. This was seen in statements such as, "time is a healer", "I'm strong", "I'm a fighter", and "it's not the end of the world".

5. Discussion:

The current study's findings will be considered in relation to the research question, existing theory and literature. Clinical implications, methodological issues and areas for future research are discussed, and the research is reflected upon. IPA can lead to unexpected themes, thus some of the literature introduced below is new (Smith et al., 2009). Due to the qualitative design, it is not possible to make causal explanations or generalisable conclusions; however an attempt is made to integrate the findings with existing literature, whilst attending to some possible transferable ideas.

This study aimed to address the research question: How do UK-based African women experience, perceive, make sense of, and manage a diagnosis of HIV during their pregnancy and subsequently?

The findings suggest that managing an HIV diagnosis during pregnancy, often in the context of being a refugee or asylum-seeking woman, is a complex multi-layered process that is significantly influenced by a range of physiological, cultural, psychological, economical, political, and social variables.

5.1 HIV as part of a wider tapestry

This theme encapsulated the complexity and significance of integrating HIV within one's story and context. This echoes Bletzer (2007) conclusions, which describe HIV as not always the primary disruptive issue, but one of multiple social problems, and Schider's argument, as cited in Lindegger and Wood, (1995), that HIV/AIDS is "the ultimate biopsychosocial phenomenon" (p.8).

The helpfulness of considering a person's life trajectory within their socio-political context, whilst attending to possible areas of unresolved and/or intergenerational trauma, experiences of stigma/discrimination, and psychosocial factors was highlighted. The importance of incorporating a person's multiple identities, as opposed to positioning HIV as their master identity (Goffman, 1963) is evident. A holistic framework was emphasised further in the absence of the women's discussions around physical health. With most of their reported concern being around psychosocial issues, this could however be a reflection of the questions asked, and/or the women overall reporting being physically healthy at the time of interview. This theme also highlights the influential role which education and religion can play in HIV.

5.1.2 Community and systemic responses

The above theme builds on existing literature which emphasises the significance of interpersonal aspects of HIV, particularly around feeling accepted,

connected, and respected. The validity of these findings is seen in overlap with previous research, which has identified social support as a significant factor explaining differences in QoL following diagnosis (Felton & Revenson, 1984). Furthermore the current analysis suggested that support groups can be experienced as central in the participant's management of HIV, echoing research which suggests that HIV/AIDS support groups can enhance self-efficacy, mastery, reduce social isolation, and emotional distress, foster greater disclosure, and increase HIV-related knowledge (Simoni, 2005; Gillett & Parr, 2010).

There is also an increasing evidence base which highlights the negative impact that HIV-related stigma and discrimination can have on the mental health of people living with HIV/AIDS, and the present study captured how actual and/or perceived stigma and discrimination was pervasive throughout these women's experiences, which mirrors Mann's (1996) idea that HIV is also an epidemic of stigma, discrimination, and denial. For these women, their experiences of stigma were influenced by wider discourses and responses, including those around HIV being an African disease, and/or associated with death, sex, and punishment.

These negative responses seemed to contribute to social isolation, rejection, and shame, and fit with Rohleder and Gibson's (2006) and Lawless et al.'s (1996) findings that MLWHA may internalise stigma, leading to a spoiled identity and self-condemnation. These external influences or voices of others seemed to become part of the women's internal dialogues. This resonates with the increasing evidence-base which highlights the negative impact that HIV-related stigma/discrimination can have on the mental health of people living with HIV/AIDS (Nyblade 2003). In many cases, these women seemed to face the moral and sexual discourses of perversity and culpability (Bredstrom, 2006) which seemed to influence their disclosure decisions

(Wiener, Mellins, Marhefka & Battles, 2007), and supports Calim et al. (2007) findings that stigma is as one of the primary factors influencing the disclosure of HIV/AIDS for women of Black African descent.

For the majority their expectations and/or fears around how others would react to their status seemed to reinforce a “conspiracy of silence” (Danieli 1984), where HIV was seen as too threatening or damaging to name or discuss.

A related striking sub-theme which emerged and has not been previously foregrounded in the UK literature, concerned the negative responses experienced by some of the study’s participants from health professionals. This resonates with a review by Nyblade, Stangl, Weiss, and Ashburn (2009) on the various forms of stigma documented in healthcare settings across the world. These experiences are particularly important as many of the sample, who were female asylum-seekers or refugees, reported having previously experienced difficult interactions and abuses from people positioned as authoritative. Conversely, the women who reported positive interactions with health professionals described more trust, hope, and engagement with services. The professional role seemed to hold a lens for how some of the women viewed themselves and HIV; particularly in the context of limited social networks.

These experiences of stigma were also extended to how participant’s felt HIV was depicted in the media and in the wider public area. The current study’s findings overlap with previous findings around the importance of media and its influence on public attitudes of HIV (Jack, 2010). Many women felt HIV and their immigration status were depicted as threatening to public health and draining of resources (Dodds et al., 2004). This theme also gives weight to the importance of one’s own and others perceptions around the consequences and cause of an illness, as highlighted by the IRM (Leventhal et al., 2001).

5.1.3 Experiencing a different story of HIV

Although anecdotally acknowledged but rarely given prominence in the HIV literature, this theme captures the power of witnessing and/or experiencing HIV in a different light, or in a way which challenges people's beliefs or assumptions. The majority of women discussed the profound impact of meeting and hearing the stories of HIV-positive people who were coping well after several years of diagnosis, and/or unexpected people with HIV such as a medical professional. This seemed to provide the women with repeated experiences of multiple perspectives, and create various identities and meanings of HIV. This fits with Yalom (1975) observations that seeing others in varying stages of transformation can provide people with hope and encouragement.

Furthermore seeing oneself as healthy, active, and/or an expert of experience seemed to carve a new sense of purpose, hope, and agency for these women. This echoes findings by Brashers, Haas, Klinge, and Neidig (2000) around how engaging in advocate and activist roles might challenge feelings of being out of control and of helplessness. The analysis also highlighted the complexities of being diagnosed with HIV during pregnancy, a time of identity transition. These women had to grapple with their new diagnosis, whilst making disclosure decisions, managing the fear of MTCT, and deciding whether to continue with the pregnancy.

5.1.4 Mother-child relationship

This theme encapsulates the complexities of being diagnosed with HIV during a time of change and identity transition, such as in pregnancy. Women had to make disclosure decisions, manage the fear of infecting their baby, make decisions around whether to continue with the pregnancy, all while grappling with their new diagnosis. These findings echo those documented by Sanders (2008).

The study's findings overlap with previous studies investigating motherhood in the context of HIV building on its legitimacy (Sandelowski & Barroso, 2003; Hebling & Hardy, 2007; Murphy, 2008). These mirrored findings include that the lives of MLWHA can be challenging, however can also be a source of protection, reason to live, and determination. Primary concerns for these women included, others' reactions towards themselves or their children if their status was known, sadness at possibly not seeing their children grow-up, whom would care for their children, and concerns around future endeavours, such as starting new relationships or having additional children. Moreover, for this group of women, these difficulties seemed to be exacerbated owing to other psychosocial and contextual factors.

A striking sub-theme which emerged for all the women was the difficulty with not breastfeeding. Despite the known medical benefits of this in reducing MTCT, the women struggled, most notably deeming it unnatural and unwomanly. Moreover the women felt that not breastfeeding impacted on their connection to their child, as well as arousing suspicion in others of their HIV status, and others labelling them as a "bad/selfish mother". These difficulties are supported by existing literature which suggests that not breastfeeding is a particular challenge for African mothers (Doherty et al., 2006; Kebaabetswe, 2007), however little is documented within the British context.

5.1.5 Capacity for resiliency

The majority of women shared responses which seemed to reflect stories of survivorship and capacity for resilience. Many seemed to have gained a sense of purpose, self-mastery, and re-assessed their goals/values, which resonates with Taylor (1983) cognitive adaptation model to threatening events. The women attributed this to support, inner-strength, availability of medication, having children, and learned ways of managing from previous difficult experiences. Furthermore religion and spirituality

were regularly indicated as having positive effects on coping. This builds on Doyal and Anderson's (2005) finding that religion can provide a sense of inner-strength for HIV-positive African people, and Frankl's (1959) ideas around spirituality providing one with a sense of meaning.

5. 2 Methodological considerations: strengths and limitations

The use of qualitative research seems to make a useful contribution to the evidence-base by allowing participants to define and explore issues important to them without being constrained by the concepts set-out in questionnaires (Dovey-Pearce et al., 2007); it also demonstrates how taking a more personal focus can develop our understanding of this phenomenon. IPA appeared to fit well with the study's aims, by allowing a rich understanding of the women's experiences. However IPA is an idiographic approach, which does not seek to find definitive or positivist answers, and additionally this study used a small, purposive sample, therefore it is not possible to make conclusions about the generalisability of these findings for the wider population. However the findings provide an insight into the salient themes of the participants' experiences in this particular study, and some themes may be transferable or springboards for future investigations. Moreover, although attempts were made to be rigorous and transparent, it is mentionable that what is offered is the researcher's interpretation, and other researchers may have given prominence to other facets.

Furthermore although this study met IPA's guidelines on having a homogenous sample, it is recognized that those who chose to participate, and in this case attend support groups, and are engaged with specialist HIV services, may have had different experiences to those who did not (Walch, Roetzer, & Minnett, 2006). In addition, it is it is acknowledged that unfortunately using the label African to define the

participant's in the current study is reductionist and implies homogeneity, within a diverse, heterogeneous group of individuals.

5.3 Clinical implications:

The current study advocates against diagnostic overshadowing and for formulating and working in a holistic way, which takes into account the fusion and interplay of multiple factors, including the wider systemic, contextual, and organisational dynamics. Also highlighted is the helpfulness of attending to clients' broader stories which considers how HIV can link, conflict, or trigger unresolved trauma and losses, and/or cultural and spiritual conceptualisations of illness and coping (Kagawa-Singer & Kassim-Lakha, 2003). The study's findings suggest that viewing clients as experts of experience, whilst attending to their resiliencies, hopes, and values. This seems particularly relevant when someone's self-story is thin and problem-saturated (White, 1990), and their defining/dominant story is that of HIV. The current study also suggests that issues around confidentiality should be given prominence, and that the way a diagnosis is delivered and managed requires careful thought.

The power of relationships for these women was also captured, which suggests that approaches which incorporate relational and contextual ideas may be more appropriate in this case.

The findings also supports the importance of understanding the meaning of HIV to the person/systems, including exploring the illness and coping scripts/narratives (Kleinman, 1988; Hardwick, 1989).

Furthermore the current study suggests that exploring interpersonal issues, such as child-care, disclosure decisions, and breastfeeding, whilst acknowledging the wider context/discourses is recommended.

The current study advocates for the importance of support groups, and of forming stronger links with community resources, including spiritual/religious organisations. These women seemed to benefit from opportunities where they could be actively involved, have a sense of purpose, and be experts of experience.

Furthermore, experiencing different stories, often of those who were unexpected and/or doing well seemed influential. It seemed that the more powerful the more experiences one was exposed to; however in some cases just meeting one person seemed to instil hope, challenge beliefs, and create new perspectives. There are numerous ways this could be promoted; however two possible ways could be through having an accessible booklet showing stories and photos of people from different walks of life living with HIV, and the other being the use of outsider witness groups (White, 1990).

Additionally the findings around these women's experiences in healthcare settings may be indicative that more HIV anti-discrimination training is needed for healthcare professionals. Furthermore the participants highlighted public perceptions of HIV being a fatal, homosexual, or African only illness, with children born to HIV-positive mothers inevitably becoming HIV-positive themselves. These misconceptions seemed to further impede disclosure; and campaigning, media awareness and education is needed to address these.

5.4 Research implications

Building on Sherr's (2010) review on fathers and HIV which confirmed the importance of relational aspects, exploration of the role of fathers and siblings in this area is needed. Furthermore, future studies would benefit from investigating these women at different illness stages, as well as comparing them to non-asylum-seeking/refugee women to establish the optimal interventions to identify and meet their varying needs. It would also be clinically useful to explore differences or emerging themes in those women who have become pregnant and/or contracted HIV from rape or whose children are HIV-positive. Moreover, the above findings could be further investigated using psychometric measures on areas including stigma, mother-child attachment, illness perceptions, coping, and resilience.

5.5 Conclusion

In conclusion, a sample of UK-based African women diagnosed with HIV during their pregnancy described a complex plethora of experiences, based on which it seems important for clinicians to (i) recognise that HIV may not always be the primary difficulty facing their clients, and may be amongst numerous other multi-faceted factors, (ii) consider systemic and contextual factors, including cultural influences, and past trauma, (iii) focus on client strengths, resources and capacity for resilience, (iv) support clients to access local resources, including support groups, (v) attend to issues around confidentiality, disclosure decisions and breastfeeding, and (vi) hold in mind the potentially powerful and helpful affect for these women of witnessing different narratives around HIV. The continuing need to counteract stigma and discrimination, including from health professionals and from the media, was also apparent.

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SECTION C: CRITICAL APPRAISAL OF THE PAPER

Word Count- 1997

Word Count with references- 2346

This section will answer four questions, each addressing a different aspect of the lessons and skills learned throughout the research project.

1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

The skills gained and developed during this project covered the whole spectrum of the research process, including selecting feasible ideas which could be practically completed in the doctorate time frame, writing a research proposal, thinking strategically about where and how to recruit participants, and choosing an appropriate methodology.

Moreover, this research built on my skills in making links with experienced professionals/peers, and in doing so becoming part of a wider specialist community. This project also enhanced my ability to review and critique an evidence-base, whilst being selective in what I chose to present or explore in more detail. Also, this was the first time I had designed an interview schedule and carried out interviews, therefore this resulted in multiple new discoveries including the importance of pacing and choice of wording.

Furthermore, skills were developed through systematically analysing the data, such as the benefits of repeated reading, and/or developing and refining emerging themes. In addition, the write-up of the research required a higher level of thinking about the structural form, succinctness, and selectiveness. Moreover, I learned about how to present, engage and disseminate this research to different audiences, including to local and wider systems.

Furthermore, I was unfamiliar with interpretative phenomenological analysis (IPA), and therefore this required multiple skill acquisition, including identifying with a particular epistemological position and developing the ability to select, link and streamline emerging themes. I feel this method has probably had a rippling influence on my formulation skills.

Additional learning points included thinking in-depth about issues of ethics including that of informed consent, withdrawal, and distress. Moreover throughout the process I tried to be continuously reflective and reflexive. These processes also enhanced my awareness to how the research was shaped and influenced by my own experiences, ideas and knowledge, and in many ways reflect part of my professional/personal journey. For example, many of my influences during this project were shaped by qualifying in narrative therapy.

This project also highlighted the way research and clinical work can complement each other and how research can bring some of these dilemmas, stories, and themes to life. Seeing this connection, which had not been illustrated as powerfully in previous research projects I have undertaken, seemed to open my eyes to potential research projects I would like to carry out or be part of in the future.

Noteworthy is that the overlaps between research and clinical work also came with a disadvantage, which I hadn't anticipated prior to conducting the research. This was around the potential for role confusion between being a clinician and of being a researcher. This was highlighted during some of the interviews where I felt an urge/rescue valency to give more, follow a different questioning path, or go into "therapist mode". Although I was able to stay in the researcher role and not get drawn into the more familiar therapist role, initially I was left feeling some disappointment and

frustration, particularly as I felt I could clinically work with some of the women. However through exploring this with my research supervisors, I was able to consider the differences between my roles, and also what some of the benefits to the participants/project gained through my dual clinician role/skills, for example providing a containing experience and/or acknowledging and validating their difficulties and strengths. Furthermore, I was able to remind myself that these women were informed of the project, and its limitations, and that they knew me as a researcher. Moreover, the women were linked in with specialist services, and when feeding back, the vast majority reported the interview process as being extremely positive, and in some cases recommended taking part to their friends. In addition, my research supervisor was able to point out how the write-up and dissemination of the study was a way to honour their voices and spread their messages.

Some future skills and/or knowledge I hope to acquire are around familiarising myself with other qualitative methodologies, such as narrative analysis and grounded theory, and other mixed methods designs. I also feel it would be beneficial to experience the NHS ethics process, as this was not required for this project, and I imagine will be required for most future research projects I immerse myself in. Furthermore, I would like the opportunity to build on my current project, and to develop skills in how to link and join up research possibilities with other peers and projects, to create a more comprehensive dense research-base.

2. If you were able to do this project again, what would you do differently and why?

Overall I feel this project met and exceeded my hopes and aims, however in retrospect and in the context of a longer time-frame, I would have liked to focus more

on an action research design. I did consult with several service-users throughout the project, so this involvement was incorporated; however given the opportunity I would have liked some service-users to be more involved in the design, implementation and dissemination processes.

Furthermore, I feel it would have been beneficial to incorporate other involved persons' perspectives, such as interviewing clinicians who deliver the women's diagnosis, and family members, such as partners, I feel this would have captured additional dynamics and themes, which may be significant to understanding wider systemic aspects of the experience of an HIV diagnosis during pregnancy.

Although there are advantages and disadvantages, I feel that there would have been some benefits in meeting with the women on more than one occasion to build on our rapport, and explore some of the emerging themes in more detail, alternatively different stories and dynamics may have transpired if I had carried out a focus group.

In hindsight, I would have prepared and thought more carefully about the differences between being a researcher and a clinician and consider how this might impact on me.

3. Clinically, as a consequence of doing this study, would you do anything differently and why?

Most of the clinical consequences of this particular study have been detailed in the Clinical Implications Section in Section B, however on a wider level and in my overall clinical practice; I feel I will focus further on building links and connections with wider organisations, including support networks, associated charities, and religious and spiritual facilities. This study also enhanced my interest and influence

from community and critical psychology areas, and re-connected me to my interest in support groups and other groups, and I imagine I will create and/or look for these opportunities in future clinical situations.

I hope to continue to use a position of curiosity and a not-knowing stance to enable themes personal and unique to the client to emerge. This was particularly highlighted through hearing the numerous different ways which the women in this study made sense of a similar experience, and how one event, such as pregnancy, can represent so many different things depending on the individual and their context. I also hope this stance will position the client as an expert of their own experience, and one which fosters their ideas and strengths.

This study also re-emphasised the importance of finding and keeping a balance of one's multiple stories, including those of resilience and survivorship, alongside those of hardship and distress. This project also highlighted the disadvantages of diagnostic overshadowing, and therefore the importance of thinking holistically about the person and both signposting to other services, but also integrating social, political, economic, cultural aspects into one's work. This study magnified the usefulness of considering wider societal discourses and their relationship to what meaning the person places on their situation/ difficulty.

Finally, the study highlighted the influential nature of education, the media, health professionals, and of others reactions, and I suspect this extends to most populations, therefore I hope to create and be open to opportunities outside of the therapy room, including delivering training, being a critical newsreader (e.g. writing to a newspaper when I disagree with an article or noticing the messages being conveyed to the public) and collaborating with local services.

4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

The research avenues I would like to explore further would predominantly be around further understanding other's people's responses and experiences to a mother/wife/daughter/client being diagnosed with HIV during pregnancy. This initially could be achieved through qualitative interviews and/or focus groups. It would also be useful to identify changing needs and themes throughout these women's life spans, particularly in the context of potential changing physical health. This would therefore involve following them longitudinally and interviewing them at different time points.

Similarly, comparing different groups of women, such as those with HIV-positive children, or those who became pregnant as a product of rape, or those who are not British citizens, through comparing emerging themes from interviews, or comparing them on measures such as on coping strategies, would be useful in informing different, more tailored clinical interventions.

Furthermore, I would be interested in identifying what aspects are particularly useful in a support group and which are less helpful. This could involve interviews focusing on these aspects or using validated measures to evaluate the groups before and after.

On a more ambitious scale, I would be interested in developing training and awareness campaigns for schools, GPs and midwives and then evaluating their effectiveness pre -and post-delivery.

I would also like to focus on what enabled many of these women to be resilient and to cope well. Therefore I would like to identify the factors involved in this process, and whether, and how these can be extended/taught to others. This could be gained through interviews with the women themselves and through interviewing other sources, such as clinician's experiences of their client's coping strategies and resiliency factors. Moreover, specific measures could be used to further investigate these women's resilience, coping strategies and/or posttraumatic growth, such as the Wagnild and Young's (1993) resilience scale, the Brief Resilient Coping Scale (Sinclair & Wallston, 2004), the Life stressors and social resources inventory (Moos & Moos, 1988), the Life Change Measure (Frazier, Conlon, & Glaser, 2001), the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996), the Stress-Related Growth Scale (Park et al., 1996), the Changes in Outlook Questionnaire (Joseph, Williams, & Yule, 1993), and The Perceived Benefit Scales (McMillen & Fisher, 1998). These could be administered using a questionnaire design, and optimally they would be compared with a control group, and/or used in a repeated measures design where the same women could complete the measures at several time periods to produce longitudinal data. This information could also be collected through qualitative interviews with the women themselves and/or clinician's experiences of their client's resilience and other related factors.

I also would like to further investigate the impact on the mother-child relationship to further identify whether this is an area that requires more attention, and if so to develop appropriate interventions. This could perhaps be explored through using the parenting stress index (Abidin, 1990) and through laboratory observations of mother-child interactions, such as through using the strange situation (Ainsworth & Wittig, 1969). In addition, self-reported data could be collected, using semi-structured

interviews and/or measures such as the parent-child relationship inventory (Gerard, 1994) and the Post-partum Bonding Questionnaire (Brockington et al., 2001).

Moreover this study highlighted the importance of one's illness representations and perceptions in their conceptualising and management of HIV. It may be useful to investigate this further using the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996). The selected measures could be administered using a questionnaire design, and could be administered at different time points using a repeated measures design. In addition women could be interviewed about their illness representations at different illness and life stages.

5. References:

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SECTION D: APPENDIX OF SUPPORTING MATERIAL

Appendix 1:

Search methods

The following E-journals and electronic databases were searched from inception to March 2010, these were PsycINFO, Web of Science, IngentaConnect, SAGE Journals online, Wiley Interscience, Cochrane Register of Controlled Trials and Cochrane Database for Systematic Reviews (4th Quarter, 2006). To avoid publication bias, a combination of online and offline search procedures were used to exhaust all resources. This included scanning references of retrieved studies and books, correspondence with key researchers, internet searches, and unpublished theses.

The following search terms were used:

1. Human immunodeficiency virus, HIV, diagnosis of HIV, personal experience of HIV, psychosocial adjustment/consequences of HIV.

With

2. Antenatal/ postnatal/ perinatal/ pregnancy/ maternal HIV/ HIV-positive mothers/ Motherhood/ mother-to-child transmission/ Caregiving

With

3. African, women of African origin, African mothers, ethnic minority, African cultural groups

Searches were limited to studies in English and those conducted in the last 30 years; to reflect the most current interventions. Studies which offered relevant information on mothers living with HIV were deemed eligible for inclusion in the

review. Some studies were deemed appropriate due to their consideration of conceptual, contextual, and cultural issues, whereas others offered examples of empirical evidence. Studies were also reviewed according to their 1) relevance to the research question, and 2) their contribution to further understanding the wider context and/or experience of the phenomenon studied. Studies focusing on women from Africa within a British context and/or African based studies were also given particular attention.

All study designs and outcomes were considered, however due to the emphasis on experience, qualitative studies and more specifically, studies using interpretative phenomenological analysis were particularly attended to.

Search outcome

Results: The search yielded 90 records. Studies deemed most relevant and up to date are examined in more detail.

Appendix 2: Interview Participant Information Sheet



Individual's experience of being diagnosed with HIV during pregnancy

Interview Participant Information Sheet

The aims of the research- We are currently studying the experience and coping strategies of African women living in London of receiving an HIV diagnosis during pregnancy. The interviews aim to gain further understanding of the difficulties and issues you faced during this time, as well as what helped or didn't help you, then and now. We hope that by hearing your voice and story, we can shape, improve and inform future research, one-to-one, clinical and group interventions for African women living in London with HIV. This study will hopefully help others who have been through similar situations as you.

Eligibility- If you are a woman from Africa (any immigration status); living in the London vicinity, who is over the age of 18, and has been diagnosed with HIV during your pregnancy, then you are eligible and welcomed to this study.

How the information from the interviews will be used- It is planned that the results obtained from this study will be published in professional journals and presented at HIV conferences, as part of a clinical psychology doctorate research thesis. If you are interested in the findings of the study, every participant can get a summary of the results sent to them, via post or email. Additionally copies will also be available at XXX sexual health reception and with XXX at XXX. The researcher will attend the antenatal support group to feedback and discuss the findings of the study. However, no specific identifiable information (names, country of origin, individual quotes) will be shared with the group. Only general themes will be discussed, ensuring that your personal privacy is protected.

What will happen if you take part? - You will be fully welcomed and respected and you will be asked to tell your experiences and stories (the questions asked have been thought about in collaboration with women who are themselves HIV positive). The interview would involve completing an information seeking questionnaire and a 1-hour discussion, at a time which is convenient for you. The discussion would be taped to guarantee accuracy but your identity will not be revealed on the tape or at any point in the research. Refreshments will be provided and travel expenses will be paid.

Confidentiality- All conversations will be anonymous and confidential, however your identity will be known by the researcher who will carry out the interview (XXXX). To ensure that your privacy is protected, all information discussed will be treated as confidential and in the write-up and future reports, no names or identifiable information will be used. Anonymous quotations will be used to illustrate a theme; however these will not be identifiable. The tape recording will be deleted immediately after transcribing. This proposal has been passed by the Salomons ethics board and the researcher will be following the British Psychological Society's guidelines on confidentiality. The only circumstance when confidentiality would be breached was if there was a significant concern for your own or someone else's safety, however this would be discussed with you first.

Looking after you - It is not expected that you should experience any distress or discomfort during the interview process, however if there are any concerns, there will be professionals available to speak with you and to consider further services of support.

If you would like to be involved with the study and are willing to take part in an interview, please complete the form attached or telephone xxxxx. If you decide to participate, you can withdraw at anytime and it will not affect your treatment.

If you have any questions about the study, questions asked, or would like a telephone conversation or meeting to discuss any of the above, please contact the researchers, at the phone numbers listed below.

**Thank you and I really look forward to hearing from you and working with you,
thank you for your time!**

People and organisations involved in the research- xxxxxx, (Trainee Clinical Psychologist), xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx Tel: xxxxxx

Dr xxxxx, (Clinical Psychologist), xxxxxxxx

Additionally xxxxxx (group facilitators) are happy to be contacted.

Appendix 3

Confidential

Consent form for participants (interviews)

Title of project: African women’s experience of being diagnosed with HIV during pregnancy and their subsequent coping strategies.

Name of researchers:

XXXX (trainee clinical psychologist) - Tel: XXXX/ XXX (clinical psychologist) Tel: XX.

Please initial the box:

1.	I confirm that I have read and understood the information sheet provided	
2.	I understand that my participation is voluntary and I am free to withdraw at anytime without my treatment being affected.	
3.	I am happy to complete a questionnaire and be interviewed about my experiences of being diagnosed with HIV during my pregnancy.	
4.	I agree for anonymous quotations to be used in the write-up of the findings.	

The interview will last about one hour. It will be carried out in English and recorded on audiotape but erased immediately after the details are transcribed to ensure confidentiality.

Name of participant: _____

Date completed: _____

Signature: _____

Appendix 4:

Interview schedule for IRP- semi-structured- follow participant (Expert of experience)

Introduction:

(Explain to participant the nature of the questions, the aim, and the length of the interview, the tape recording, and confidentiality. Ensure they know they can take a break or withdraw. Rapport building and answer any questions).

Past focused (based on illness representations theory)

Question- How did you learn of your diagnosis?/ Can you tell me about your diagnosis experience? Prompt if necessary- Who told you? Where were you? How you felt, thought, what you did, what was your biggest worry? Were you aware that there was a possibility you were HIV positive? What treatment options were you given? Which services were you told about?

Question- What did having HIV mean to you?

Prompt if necessary - What did you think about HIV prior to hearing your status? What image did you have of people having HIV or how would you have described HIV to others? What did you believe that the consequences of the illness would be? What ideas did you have about the causes of HIV? If your family/friends know what has their reaction been, if any, to your diagnosis?

Question- How do you think the experience of being diagnosed with HIV during pregnancy has impacted on you as a person and on role as a mother?

Question- What changes have you had to make, if any, to adjust to living with HIV?

Prompt if necessary - how did you feel about the treatment options given to you, such as not to breast feed? how if any has it affected your quality of life?

Question- What does HIV mean to you now?

(Prompt if necessary - how do you feel/ think about HIV) / Is there a difference in how you are feeling now in comparison to how you were feeling when diagnosed? Can you tell me how and why you feel that is? If the meaning of HIV has changed, what has facilitated/influenced the change?).

Interested in coping strategies/ protective factors/ resilience

Question- How do you feel you are coping now with living with HIV?

Question- When you have difficult feelings or worries how do you try to cope with them, what do you do?

Prompt if necessary - (Internal/ external coping mechanisms/ cope alone with others/ avoidance/ active coping)

Question- What do you/ did you feel might help / helped you cope more effectively?
(Prompt if necessary - What has helped you most with coping? What has helped you be resilient?)

The group

Question- Do you feel the HIV antenatal group has been helpful/ unhelpful? If so, in what ways?

Prompt if necessary - What aspects did you value most/least?

Question- How do you see yourself in the future? (What do you hope/ wish for)

Question- If you had a friend in the same situation or could give some advice to HIV services, what would you say/ recommend?

Question- Is there anything else you would like to tell me that I have not asked about?

Ask the participant how they are feeling/ what their experience was of the interview process? If they have any questions? If they need any further support? Thank them and explain the feedback procedure.

Appendix 5: Demographic questionnaire completing following interview (some completed verbally/ answers were optional/ information collected to try and situate sample further).

Some Questions about You:

Confidentiality and Anonymity: All answers will remain confidential and are anonymous if included in the write-up of this research project.

Instructions: Please provide a response for each of the following questions by ticking the circles:

1. **What is your age?** (In years) _____

2. **What is your sex?** Female Male

3. **What is your partnership status** (please tick one circle below)?

Single Married Separated Divorced
Widowed In a relationship (living together) In a
relationship (not living together)

3b. **Have they got HIV?** (Please circle) Yes No Don't know

4a) **Living arrangements: Do you live alone?** Yes No

4b) If **No**, do you live with (please tick as many as apply)

Partner/ spouse Parents Relatives Children Others (Please specify who:) _____

4c) **how many people are living in your household including you?** _____

5. **If you have any children, please indicate how many:** _____

6. **With which racial or ethnic category do you identify?** Black African Black Caribbean White African Any other mixed background (Please specify): _____

7. **What is your country of origin?** _____

8. **How long have you been living in the UK?** _____ **Your Age at arrival in UK** _____

8b) If any, what tribal grouping do you identify yourself with?

9. What is your immigration status? (Please circle appropriate term) a)

Asylum seeker b) refugee, c) applying for compassionate leave, d) British citizen e) _____
other

9b) If not a British National what brought you to the UK? (E.g. political refugee, choice, to study) _____

10. Is English your first language? Yes No If No, which language is your mother tongue? _____

11. What religion or faith do you most closely identify with? _____

12. Please tick any educational qualifications gained?

No formal educational qualifications O-levels/ GCSEs or equivalent A-levels or equivalent Diploma or equivalent Degree Masters Degree or higher

13. Are you currently employed? Yes No

If yes, please state the type of work e.g. part time or voluntary _____

14. How long have you been attending the antenatal group?

15. How many times have you attended the antenatal group?

16. When did you first test positive for HIV? Month _____ Year _____

17. If you received your diagnosis during pregnancy, how many weeks pregnant were you? _____

Some Questions about your Health

1. What was your last CD4/ White blood cell count result?

Less than 50 51-200 201-500 501 and above Don't know

2. What was your last viral load test result?

Undetectable 51-1000 1001-10,000 10,000- 50,000 50,001- 100,000 Don't know

3. Are you currently taking any anti-HIV drugs, also known as triple therapies or combination therapies? Yes No

If Yes, how many _____ Date/s when started _____

4. Do you have any physical symptoms or drug side-effects?

Yes No

If yes, please list:

Thank you for answering the above questions!

Appendix 6:

Table1- Participant demographic information (The names used to represent the participants are pseudonyms). Some information has been excluded to ensure that participants can not be identified.

Participant pseudonyms	Mary	Grace	Shona	Esther	Josephine	Kabira
Partnership status	Relationship (not living together)	Single	Single	Single	Married	Single
Does your partner have HIV?	No	N/A	N/A	No	No	N/A
Living arrangements	2 people (1 child and participant)	5 (Participant and 4 children)	5 (3 housemates and baby)	Alone with baby	Participant, husband and 2 children	5 people (Participant, step father, sister, and child)
Number of children	2	6	1	1	2	1
Did you know people with HIV	A few from services but only 2 close friends. Didn't know anyone before.	Yes many through services and family members	Yes many through services and family member	Yes many through services	A few- I used to go to a lot of groups	Yes many through services
Length in UK	7 years	9 years	2 years	3 years	11 years	10 years
Immigration status	Asylum seeker	British citizen (previously an asylum seeker)	Student visa	Asylum seeker	Indefinite leave to remain (previously an asylum seeker)	Student visa expired now seeking asylum
Reason for coming to the UK	Marriage	Asylum seeker- war torn	Study and relationship	N/A	Study	Study
Religion/faith	Muslim/ Buddhist	Muslim	Christian	Christian	Christian	Catholic
Educational qualifications	School- left at 15	School- married at 15	Masters	Secondary school	O-levels and diploma	Degree
Are you currently employed	No, status does not allow for work	No, does do some volunteering and courses	Not currently	Not currently as not permitted to work	Not currently	Studying

How long have you been attending antenatal group for?	3 years	7 years	10 months	7months	6 years	3 years
How many times have you attended the antenatal group?	Approx 25-30 times	Approx 70	10 times	7 times	About 50	Approx 25-30 times
Are you linked in with any other HIV/community services?	A counselling /advice	Several support groups	Several support groups for African mothers	Several support groups for African mothers	No	No
How long ago were you diagnosed?	3 years ago	7 years ago	10 months ago	3 years ago	2 years	2 years ago
What stage of your pregnancy were you in when you were diagnosed?	At 3 months	At 5 months	12 weeks	4 months	4 months	5 months
What was your last CD4 count, a) less than 50, b) 51-200, c) 201-500, d) 501 and above, e) don't know?	201-500	201-500	501 and above	501 and above	Below 40	Over 700
What was your last viral load, a) undetectable, b) 51-1000, c) 1001-10000, d) 10000-50000, e) 50001-100000, f) don't know?	50,001-100,000	50,001-100,000	Undetectable	Undetectable	N/A	Undetectable
Are you currently on anti-HIV drugs?	Yes	No	Yes	Yes	Yes	No

Participant table continued..

Participant pseudonyms	Halina	Najah	La-Tosha	Batu	Bebi	Camille
Partnership status	Single	Single	Married	On and off relationship	Married	Single
Does your partner have HIV?	Yes	Not sure	No he is negative	Yes	No	N/A
Living arrangements	Participant and 2 children	Participant and 1 child	Participant , husband and 2 children	Participant, two teenage daughters, a younger daughter and a newborn son.	Participant , husband and 1 child	With my child
Number of children	2	1	2	4	1	1
Did you know people with HIV	Yes many through services and family members	Yes few through services	Yes few through services	Not many	Not many	No
Length in UK	11 years	6 years	8 years	19 years	10 years	5 years
Immigration status	asylum seeker	asylum seeker	Refugee	Asylum seeker	British citizen (previously an asylum seeker)	Refugee
Reason for coming to the UK	Asylum seeker- war torn	Study/ better life for child	Asylum seeker- war torn	Arranged marriage	Asylum seeker- war torn	Civil war
Religion/faith	Christian	Christian	Catholic	Christian	Muslim	Christian
Educational qualifications	O-levels	Didn't finish secondary school	Didn't finish secondary school	Secondary school and some college courses.	Secondary school and some college courses.	Didn't finish secondary school
Are you currently employed	Studying a degree and doing relevant voluntary work	Yes	No	No	No, studying	No
How long have you been attending antenatal group for?	1 year	5 years	On and off for 7 years	I attended for 3 months when I was diagnosed	1 year	2 years

How many times have you attended the antenatal group?	Twice	10 times	I don't know	3 times	9 times	7 times
Are you linked in with any other HIV/community services?	Several support groups	No	No	No	No	No
How long ago were you diagnosed?	5 years ago	6 years ago	8 years	6 years	7 years	1.5 years
What stage of your pregnancy were you in when you were diagnosed?	At 2 months	At 7 months	At 4 months	At 3 months	At 3 months	At 4 months
What was your last CD4 count, a) less than 50, b) 51-200, c) 201-500, d) 501 and above, e) don't know?	Not sure but good	Over 700	Over 700	Over 700	Over 700	N/A
What was your last viral load, a) undetectable, b) 51-1000, c) 1001-10000, d) 10000-50000, e) 50001-100000, f) don't know?	Not sure but good	Not sure but good	I don't know	I don't know	I don't know	I don't know
Are you currently on anti-HIV drugs?	Yes	Yes	Yes	No	Yes	Yes

Appendix 7:

The below has been removed to ensure confidentiality.

Excerpts extracted from further contextual information relating to individual participants in attempt to situate the sample

(To preserve confidentiality and anonymity some details have been omitted, and only 2 women have been presented) permission was given to include the below:

Appendix 8- An example of a full interview transcript for Grace after initial coding

This has been removed to ensure confidentiality.

Appendix 9- Chronological List of Themes which emerged – Interview two- Grace

Past traumatic experiences

HIV as part of journey/ one facet of a whole person/ get to know me not just HIV

Prayer led me to be rescued/ prayer as saviour

Difficulties of mastering a new country/ disorientated/ alone/ confused

Pregnancy as shock/ pregnancy as product of rape/ Pregnancy as a mixed experience

Discourses around HIV as death/killer

Trauma of multiple family losses

End of the world/ hopeless/ waste away/ life is pointless

Traumatic experiences

HIV linked with death

Power of witnessing others stories/ People in positions of power shifting perception

Challenge of not breastfeeding and the financial implications

Importance of relationships/ social support

Importance of being treated as human/ connecting with others

The power of witnessing others doing well with HIV

Seeing others doing well and living healthily as source of strength

Support groups being a place to meet others

Time as a healer

Expert of experience- Active coping/ taking control/ being an advocate/ helping others

Capacity for resilience

Support groups as important

Seeing others doing well/ not alone

Engaged with community

Expert of experience/ connecting with others/ gives purpose.

Complexity of not breastfeeding/ discourses around being a selfish mum/ children's health as priority

Importance of social support/ connecting with the community

Impact of stigma

Awareness campaigns/HIV isn't catchy

HIV as part of one's identity/ integrated

Past trauma

Capacity for resilience- survivorship

HIV as a horrible death

Feelings of depression/ seeing and hearing things

Social isolation/ psychosocial difficulties

Religion as source of strength/ faith/ Religion as a coping strategy however Stigma- HIV associated with sexual perversity

Image being important- a signified of being healthy, can't be identified as HIV-positive

Disclosure decisions as challenging

Fear of abandonment and/or rejection

Children's fears for their mother's health

HIV being something to keep a secret

Psychosocial stressors- poverty/ son being deported

Self as strong/ as a fighter

Coping strategies- Praying and religion/ active coping/ expert of experience and witnessing others

HIV as not the end of world/ can live healthy/ allowing oneself to think of a future

Need for professionals to respect confidentiality

Mixed experiences from health professionals

Positive stories of future

Appendix 10- Theme Table for Interview 2- Grace (some initial clustering of themes from Grace's transcript)

Psychological consequences of diagnosis of HIV/ initial reactions/ emotional responses

Feelings of depression/ seeing and hearing things

Shock

Sadness/ Fear

Suicidal ideation

Fear of abandonment and/or rejection

A traumatic history/ past traumas/ contending with numerous social problems/ psychosocial stressors.

Past traumatic experiences

Pregnancy as shock/ pregnancy as product of rape/ Pregnancy as a mixed experience

Difficulties of mastering a new country/ disorientated/ alone/ confused

Trauma of multiple family losses

Traumatic experiences

Challenge of not breastfeeding and the financial implications

Social isolation/ psychosocial difficulties

More to me than HIV/ HIV as one thread of one's life/ HIV as not the dominant story

HIV as part of journey/ one facet of a whole person/ get to know me not just HIV

HIV as part of one's identity/ integrated

Role of religion and prayer

Religion as source of strength/ faith/ Religion as a coping strategy however Stigma- HIV associated with sexual perversity

Prayer led me to be rescued/ prayer as saviour

Pregnancy as associated with trauma/ challenges to mother-child relationship/ Child as priority

Pregnancy as shock/ pregnancy as product of rape/ Pregnancy as a mixed experience

Challenge of not breastfeeding and the financial implications

Complexity of not breastfeeding/ discourses around being a selfish mum/ children's health as priority
Children's fears for their mother's health

HIV conceptualised as death/ narratives and discourses of HIV being death

Discourses around HIV as death/killer
End of the world/ hopeless/ waste away/ life is pointless

HIV linked with death
HIV as a horrible death

Living proof that one can do well with HIV/ witnessing new stories of HIV

Power of witnessing others stories/ People in positions of power shifting perception
Seeing others doing well/ not alone
Seeing others doing well and living healthily as source of strength

The power of others/ other's reactions/ other's responses/ social support as key/ challenges of disclosing to others

Importance of relationships/ social support
Importance of being treated as human/ connecting with others
Support groups being a place to meet others

Support groups as important
Engaged with community

Fear of abandonment and/or rejection
Importance of social support/ connecting with the community
Impact of stigma- HIV being something to keep a secret
Awareness campaigns/HIV isn't catchy

Need for professionals to respect confidentiality
Mixed experiences from health professionals
Disclosure decisions as challenging

Mastery over one's life/ being an expert of experience/ active coping style

Expert of experience- Active coping/ taking control/ being an advocate/ helping others
Expert of experience/ connecting with others/ gives purpose.

Resilience/ inner-strength/ coping well

Capacity for resilience
Survivorship
Fighter
Inner-strength
Prayer and religion
Active coping
Expert of experience

Image being important- signifier of health, can't be identified as HIV-positive
Time as healer
Positive stories of future
HIV as not the end of the world/ can live healthy and think of a good future.

Appendix 11- Example of an interview transcript before initial coding- Shona's transcript:

The below has been removed to ensure confidentiality.

Appendix 12- Examples of some of the process of organising emerging themes- See Appendix 13 for examples of related extracts.

Abstraction leading to the development of a super-ordinate theme

Emotional responses to a diagnosis of HIV/ psychological consequences of a diagnosis of HIV/ initial reactions to a diagnosis of HIV

Depression

Shock

Self-neglect (not eating, drinking, preparing self to die, not washing)

Paranoia

Tearfulness

Not sleeping

Sadness

Disappointment

Fear

Disbelief

Hopelessness / contemplating suicide

Assuming diagnosis will lead to imminent death

Dissociated/ cut-off/ numb

Terror/fear/anxiety/dread/uncertainty at others responses

Subsumption leading to the development of a super-ordinate theme (emerged from sub-theme around other's responses, felt it required a super ordinate theme itself as various sub-themes attached and occurred in all the women's stories).

Community and systemic influences and responses to HIV

Significant relationships

Social support

The role of health professionals

Media influence

HIV-related discourses

Appendix 13- A wider selection of quotes which correspond with each master and sub-theme

<p>HIV as part of a wider tapestry</p>	<p>Emotional responses to the diagnosis of HIV</p> <p>Batu: After that I was very bad, I self-neglected, I didn't care about myself, I starting giving things away, it was like I was preparing myself to die.</p> <p>Camille: I didn't care about me, I had no energy to get dressed, bath etc.</p> <p>Mary: My mind was blank, I couldn't think. My brain just stopped.</p> <p>Camille: I just stared, I felt nothing.</p> <p>Shona: I never expected it, and I was so in shock</p> <p>Bebi: I was so shocked; I didn't think it was true so I got tested lots more times to make sure it wasn't a mistake.</p> <p>Halina: I felt very sad.</p> <p>Najah: I was so shocked and sad.</p> <p>La Tosha: I couldn't eat or sleep and felt shocked and sad.</p> <p>Mary: My mind was blank, I couldn't think. I ignored it and thought maybe it is not true, maybe they have made some sort of mistake</p> <p>Bebi: I didn't think it was true so I got tested lots more times to make sure it wasn't a mistake.</p> <p>Mary: Since the day I was diagnosed, I feel terrified, fear, depressed and scared.</p> <p>Halina: I felt very scared.</p> <p>Grace: I said HIV positive, ok then it is the end of the world, that's what I told the doctor, I wanted to commit suicide; I wanted to come out and die.</p> <p>Esther: So I was like the world has ended (<i>Starts crying</i>). For some time I couldn't talk, I was very very very shocked, I didn't want to live anymore.</p> <p>Najah: I was awful, I wanted to kill myself.</p> <p>Najah: I was crying the whole time, I was depressed, I couldn't eat, I couldn't sleep it was terrible.</p> <p>Camille: I felt so low; I couldn't even bring myself to eat.</p> <p>Kabira: I do have times when I feel low and depressed and I think why me, I</p>
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	<p>see people doing worse things than me and think why not them.</p> <p>Najah: I thought there is no way I could have that kind of sickness</p> <p>Batu: I thought that it only happens to certain people, like people who sleep around and that it couldn't happen to me.</p> <p>Bebi: I was thinking I am a good girl, I haven't slept around, how could I have this. I thought this can't be me, I am a healthy person, I am never sick.</p> <p>Najah: I was walking around paranoid and talking to myself.</p> <p>Grace: Yes I became so depressed, seeing things, hearing voices</p>
	<p>Traumatic experiences</p> <p>Mary: All my life has been abusive by men.</p> <p>Grace: This is the bullets on my face (pointing to her face) and one entered into my mouth and I was also kicked into the chest. () They did what they wanted with us, started raping us, beating us, that's where I got it from.</p> <p>Kabira: It was hard having the diagnosis, a baby and a relationship breakdown</p> <p>Halina: I was raped lots of times it was horrendous.</p> <p>La Tosha: I had this thing and then my partner started being violence to me.</p>
	<p>Psychosocial stressors</p> <p>Najah: the HIV and immigration was too much.</p> <p>Grace: They say my son has to be deported, that is why my CD4 count has come down.</p> <p>Camille: I live in an awful place, I can't work and I am sure this is making me unhealthier; there isn't even room for my child to play.</p> <p>Josephine: It was difficult coming here and living like a poor person.</p> <p>Halina: the language, the culture, the weather it is all different.</p>
	<p>Educational experiences</p> <p>Shona: I never thought I would die, that was the number one thing. Back home I worked in a youth service and joined and volunteered an anti-HIV campaign and they taught us many things, the positive aspects of HIV, the stigma, the myths, what people think isn't how it is, and I believed them and took it in.</p> <p>Shona: What gave me strength was the lectures and training I was given back home and I know with medication that it wouldn't kill me.</p>

	<p>Josephine: When I was doing my O levels people came in schools and taught us about HIV, telling people what to do, about condoms, so I learned more about it and my mum was a nurse so she used to tell me about all the different types of people she saw so I really learned from that.</p> <p>Camille: a lot of the posters and talks in school I had were useful and showed me a different side of HIV.</p>
<p>Community and systemic influences and responses to HIV</p>	<p>Significant relationships</p> <p>Esther: He couldn't believe it, he said I don't know what you are talking about, and he said it could be a mistake, he said to come, but myself I was scared to go and meet him. He was very surprised and scared that he might be infected. But after he found out he was negative.</p> <p>Esther: he said I have to terminate the pregnancy</p> <p>Kabira: When I was told about the HIV I was with my daughter's father and I told him to go and get tested but he refused and then he left us, still today he refuses to get tested.</p> <p>Bebi: I told my husband and he was very shocked, he thought I was sleeping around and so he left me for 3 months abandoned, it was a very difficult time, but then he came back and apologised and since then he has been so so wonderful and supportive.</p> <p>Grace: he said if you are HIV I will just leave you and go away to another home</p> <p>Kabira: I told my mother and she just thought it isn't true, she is in denial. she has never mentioned it again</p> <p>Batu: Although I did tell the father of my child, my second partner, and he was not good and left.</p> <p>Mary: He (partner) keeps an eye on me the way I play with her or kiss her, or when I give her a bath or change her nappy, he is scared I might pass it on to her accidentally. Or when I have my period he is worried about her.</p> <p>Najah: I told one woman in church and she reacted so badly that I had to stop going to that church</p> <p>Shona: I haven't told anyone, my family know nothing, because back home they think of me very highly, it is better our relationship stays good.</p> <p>Kabira: If I met someone what do I say? Will they accept me?</p> <p>Kabira: even when you go to the dentist the form asks for medical details, and I'm always scared and debating thinking what will happen if I say yes. Do I say it or do I not, most of time I choose not to say it.</p> <p>Batu: I still haven't told my family, I don't want to worry them.</p> <p>Batu: I haven't told me children and I really must I just don't know how to.</p> <p>Mary: No I don't know how to find the words. Because I don't know if they</p>

	<p>will be accepting or rejecting but I think rejecting.</p> <p>Bebi: I am worried how they will react and also people gossip a lot, you tell someone something and next minute they tell someone else.</p> <p>Kabira: It feels like a burden, a secret, but I don't know when I would be ready to tell or if I will be or if someone else will tell it for me, that's why I've kept it.</p> <p>Najah: You know sometimes I test people, I tell them things and see what their reaction will be so I can think about what their reaction might be if I told them.</p> <p>Bebi: Sometimes it is difficult because we have to be careful and I want to protect him and keep him healthy, so sexually, always using a condom etc can feel like a punishment and prison.</p> <p>Camille: It also hurts me that I can't be a full woman, I am worried about sex and so I don't enjoy it because I am so panicked.</p>
	<p>Social support</p> <p>Mary: They talk about what we can do to help you get through this, how you can live with it and be confident, so that they say I'm HIV and so what.</p> <p>Grace: To see people in the same situation, who are good, healthy, who have kids helped me be strong and confident.</p> <p>Shona: it gives you courage and a boost.</p> <p>Josephine: you meet other people who are HIV people, get educated, learn new things, and understand HIV more. It is great to hear other people's experiences and vice versa, you learn a lot from each other.</p> <p>Kabira: I could be open and relaxed, take a breath, no one is there to judge, as they are just like me.</p> <p>Camille: they are a great opportunity to not be alone in this thing.</p> <p>Esther: Without them I would be lost, they keep you looked after and known.</p>
	<p>The role of health professionals</p> <p>Mary: with the other women the midwives were talking a lot and playing with the baby and with me they just came in checked and left.</p> <p>Shona: one nurse when I gave birth and was in a lot of pain and I think she stigmatised me, her face was not inviting at all, I said please help, and she said no take care of him yourself and then she left, I think she treated me differently.</p> <p>Kabira: when I got there she looked at my book and said what is this? And I</p>

	<p>said I am HIV positive and she said oh don't come back here again, don't come back here again. That was the worst experience for me.</p> <p>Halina: the midwives treated me differently they threw my sheets away and I was only allowed to use certain showers and stuff.</p> <p>Grace: Some people are not trained, when I was bleeding, as soon as they knew about it, they cleaned everywhere, put on masks on, sprayed and everything. And that was the ambulance people!</p> <p>Bebi: They looked at me like I was a piece of shit.</p> <p>Grace: I did have experience with a trainee doctor who broke the news in front of someone from my country, so that was awful!</p> <p>Mary: I'm quite concerned about my letter box, I live in flats and someone might see the letters.</p> <p>Shona: I like professionals because of the confidentiality which binds what they say.</p> <p>Camille: One time I went to a doctor and the secretary looked at me funny and then when I sat down I heard her say to the other one, she has HIV, and I thought everyone can hear!</p> <p>Kabira: The staff there were very professional, I was among other people, there was even a time when my daughter needed medicine but I had visitors and so they waited for everyone to go and then called me into a room to say they didn't want to give her the medicine in front of everyone in case I didn't want people to know or ask questions, I felt so relieved and happy they thought about that.</p> <p>Josephine: The consultant he is very nice and supportive so he helped a lot. He doesn't rush you; he does his job wholeheartedly, he supports you, takes time to get to know you.</p> <p>Halina: It was much better, the midwives and doctors were fantastic, they treated me so well and I felt supported and confident that my baby would be ok.</p> <p>Bebi: My medical team are very good and they are supporting me in trying for another baby.</p>
	<p>Media influence</p> <p>Halina: [] I saw this program and it was about living healthily with HIV, and I felt overjoyed, and wished everyone could watch it to know that HIV isn't just death and disaster.</p>

	<p>Najah: [] I was watching Jeremy Kyle and there was an HIV-positive white woman and she told her husband and he hugged her and said he loved her. That was the first time I saw HIV on the TV especially on a white woman, it was special.</p> <p>Esther: It should be on TV and the radio more and people should know its not a awful thing and we don't all look like we are wasting away.</p> <p>Camille: There should be more awareness to show it's the same as something like diabetes.</p>
	<p>HIV-related discourses</p> <p>Kabira: I thought I'm going to die, a terrible death.</p> <p>Halina: I couldn't believe it, I just thought this is it, I am going to die, in 2 months I will be gone. That's the mentality in Africa, you will be thin as a finger and it will eat away at you and you will be gone quickly. () In Zimbabwe my aunt and her baby died of HIV, I helped nurse them towards the end and they were both so awfully sick, that's what I thought would happen to me and my baby.</p> <p>Bebi: I was scared of dying a horrible suffering death, I want a safe death.</p> <p>Camille: I thought that's it, my time has come.</p> <p>Mary: Yes, death, dying, coffins.</p> <p>Grace: my mother died of HIV, my father died of HIV, my sister of HIV, my brother of HIV, my sister of HIV; we were 7 and now are 2, all my sisters died of HIV.</p> <p>Najah: It meant death</p> <p>Esther: End of the world, death, pointless</p> <p>Batu: I did tell one man who wanted to marry me and I told him you can't because I have HIV and he was very nice and understanding and said he would pray to G-d to take the HIV away from me.</p> <p>Camille: I thought what have I done to be punished, I've always tried to be a good person.</p> <p>Shona: They believe in witchcraft, those fetish things, that someone is cursing you; someone got upset and sent it for you. So my sister believes someone sent it to me out of wickedness.</p> <p>Josephine: People in my country think something is doing juju (curse) to them.</p> <p>Mary: HIV in my country and for my people means you are dirty, you sleep</p>

	<p>around. You go be like a prostitute.</p> <p>Shona: HIV is seen as so different to cancer or diabetes, I think because sex is seen as the main cause and sex is seen as immoral.</p> <p>Grace: I am a strong believer. I pray.</p> <p>Halina: I go to church to which is helpful.</p> <p>Bebi: religion is important in the house, I believe HIV is my destiny and G-d planned it.</p> <p>Esther: It is out of my control, it is in the hands of the powers above</p> <p>Camille: I pray everyday and he looks after me and makes me keep going.</p>
<p>Experiencing a different story</p>	<p>Being accepted and embraced</p> <p>Grace: He is the person who made me stronger, he said no worry, people here live, people here are ok, they get medication, and they have children. He put that thing in my mind that I would live. He wanted to share with me a cup of drink and I said no you will be HIV and he said no I will be ok.</p> <p>Kabira: My sister hasn't treated me any differently, she loves my daughter, and she hugs me and kisses me. () We went away and some friends were talking about HIV and she came up with all these facts, so she must know more then she said, she must have read what I bought home which made me feel good.</p> <p>Camille: He reached out and held my hand and I knew it would be ok cos he touched me and smiled</p>
	<p>Healthy lifestyle</p> <p>Josephine: here if you do what the doctor says and take medication then you are ok, so knowing that helped me, I know medication is there and available.</p> <p>Bebi: I had a friend in Africa who had HIV and all 3 of their children died from AIDs because of no medication, so in Africa it is very different and horrible but here it is so much better.</p> <p>Mary: I eat everything and anything I can think of to make me healthy. I eat extra then I normally eat, I do a lot of walking instead of the bus, I am trying to keep myself healthy and it does help, it really does, my CD4 count was really good</p> <p>Halina: I think living healthily, walking, eating well, swimming and keeping busy with my children and studying</p> <p>Grace: I say I am HIV positive and no one believes me cos I look good. The other day I told the nurses and they said no!</p>

	<p>Mary: I try, I don't like people to see me looking sick, or down. I try to keep myself healthy at all times, if one day I don't look good I just put all the makeup on. It makes me feel better about myself.</p> <p>Camille: I look good so I am happy, as long as people can't see a stick thin thing that looks sick.</p>
	<p>Expert of experience</p> <p>Grace: I went on a course, telling of my story, how healthy I am, and I went on a course about choosing medication and another course on side effects of medication; I am choosing my own type.</p> <p>Josephine: And now I can help the others who are worried or newly diagnosed</p> <p>Kabira: they have helped me in more ways too; they have trained me in facilitating</p> <p>Halina: I am in my final year of a degree where you learn how to empower communities</p> <p>La Tosha: In the future I want to help people with HIV in Africa.</p> <p>Bebi: I am going to college to be a social worker so I can help other people.</p> <p>Grace: she talked to me and showed me her letters of how she was diagnosed, she has been here for almost 18 years, she had had a child, she showed me the papers, and she said can you tell? I said no</p> <p>Batu: I also met some inspirational people (named the group facilitator) who spoke confidently about being HIV themselves and they looked good and were happy so that made me feel better. They made me think if they can do it I can do it.</p> <p>Mary: see my role model, she has 3 children and is about 40 and still looks good and healthy. Every time I look at her and think of HIV I feel better, it keeps me going.</p>
	<p>HIV can touch all</p> <p>Grace: Then there is a doctor who came to me and he said to me I am HIV positive, a doctor?</p> <p>Halina: This white woman came to counsel me and she was telling me everything will be ok, people live a long time with HIV and that there is medication available. She compared it to diabetes. I thought she was lying to me and I couldn't believe it but then she told me she had HIV and was living healthily with her healthy children, and that was a big moment.</p> <p>Najah: I was watching Jeremy Kyle and there was a white woman with HIV and she told her husband and he just hugged her and said he loved her, that was the first time I saw HIV on the TV especially on a white woman.</p>

	<p>Camille: I used to think it was just people like me but now I know it happens to all types of people.</p>
	<p>HIV as not the master identity</p> <p>Grace: it is part of my life and I will take my medication as being my best friend (Smiling).</p> <p>Najah: I have HIV; it is part of me like a piece of clothes.</p> <p>Camille: You accept it as part of you but not all you and get on with it.</p> <p>Esther: Sure I am HIV-positive but there's a lot more to me than just that.</p> <p>Halina: I think now there are times I don't even think of the HIV.</p> <p>Najah: Sometimes I wake up and don't remember I have it or I pretend I don't have it but then I have to take the medication and that is a constant reminder.</p>
<p>Mother-child relationship</p>	<p>Child as protective factor</p> <p>Kabira: I didn't ask about anything to do with me, my main concern, 100% was my daughter, for her to be healthy, I did whatever I had to for her.</p> <p>Mary: Every day I go through a lot and the only thing I am thinking of is my son back home, that's what is stopping me from killing myself.</p> <p>Shona: I made up my mind that nothing is going to happen to my baby.</p> <p>Esther: My baby; he is the only thing I have got.</p> <p>Kabira: Having her has made me better, she gives me a reason. I just want the best for her, I hardly think of myself.</p> <p>Halina: my baby, she kept me alive, she was my priority.</p> <p>Najah: It changed my life forever, had I not been pregnant I would have killed myself.</p> <p>Josephine: I think it made me closer to my daughter, I was on my own with her, so I was just focusing on her, the things we could do together, and making sure she was healthy. It has made me see her as even more precious.</p> <p>Halina: I feel it was special, I loved her more because I thought without her I wouldn't have known and G-d wanted me to know, and she kept me going.</p> <p>Camille: she is my inspiration. She keeps me going.</p> <p>Kabira: My daughter, having her around and seeing her. If she wasn't there it would be a different story,</p>

	<p>Fear for child's health and future</p> <p>Halina: I felt very scared and sad</p> <p>La Tosha: I wanted to have an abortion as it wasn't fair for the baby and I was worried that she would be sick</p> <p>Mary: I'm thinking about my baby, is she going to be infected, is she going to be ok. It's hard because at that moment I can't really think of myself, what I'm thinking is just my baby.</p> <p>Batu: I was thinking I am going to die tomorrow, who is going to look after my children.</p> <p>Kabira: If I think of myself, I think will I go to an age when I will see her? If I pass away what will happen to her? Will I see her grow up?</p> <p>Bebi I was so worried to not see my son grow up.</p> <p>Kabira: () Sometimes I am cooking and if I cut myself I panic, last time I locked myself in the bathroom, I didn't know how to cope with it, I was scared to infect people.</p> <p>Bebi: It was hard because I was worried to touch my son, or feed him or sleep with him, it took me a long time to be ok and even now if I cut myself I throw the knife away, I clean everywhere all the time.</p> <p>Kabira: I would be so scared to give it to someone else, to kill someone else.</p>
	<p>The complexity of not breastfeeding</p> <p>Mary: Not breastfeeding was horrible because I felt like something was missing; we weren't connected, because a lot of things went through my mind with this HIV thing.</p> <p>Grace: I said as an African woman I have to breastfeed!</p> <p>Shona: Everyone was asking why aren't you breastfeeding? I kept on defending myself and saying different excuses. It hurt me so much, even if no solution to HIV, a solution to breastfeeding would be so important. I found the pain so much and for African women it is not normal. My baby cried so much and usually if you give them a breast they will stop but he wouldn't and I couldn't. I thank g-d I didn't have him in Africa how would I have explained it to my mum</p> <p>Halina: You see in Africa people know if you don't breastfeed its cos your positive.</p> <p>Batu: I used to cry when the baby cried as I felt I was missing out on something. It was very difficult; it felt less close and womanly.</p> <p>Grace: Yes it is like you are a selfish mum, people used to ask me why are you not breastfeeding? They say it's not normal, it's bad.</p> <p>Camille: It is horrible you don't feel the same as others it makes you less</p>

	connected.
	<p>Pregnancy as a mixed experience</p> <p>Josephine: Mixed because I wanted a baby and was happy but now I had so much to think about and was worried.</p> <p>Mary: I don't know how to say it, it was different. With my son I felt all the excitement, I couldn't wait to hold my son, but with her I'm terrified that what might happen to her, what if something happened to her, how am I going to live with it, cope with it, I don't have a clue. I was just so terrified.</p> <p>Camille: I always wanted a baby but never like this, it has turned my happiness into worry. I hope this thing I have won't ruin things for me and my baby.</p> <p>Bebi: How can I explain this pregnancy doesn't feel like how it should, I'm more worried than excited.</p> <p>Esther: I look at other people and they all seem so happy, with their bellies and me I also feel happy but it is made bad with this HIV thing</p> <p>Halina: It is a bit of both, depends on the day.</p>

Appendix 14- Excerpts from reflective research diary:

February 2nd 2010:

Today I met she walked into the room and had such presence, I was taken a back by her boldness and openness, somehow I was expecting a women to enter the room and present as quite unsure and low, but instead I was confronted with someone who proudly shouted her HIV status with a beaming smile. She proceeded to freely telling me her life story linking it to how she came to be diagnosed with HIV, it felt really important to her for HIV to not be seen in isolation. Hearing the atrocities she had experienced whilst she showed me her scars and bullets marks I felt such a mix of emotions, I felt angry at what violations she had been through and it bought my human rights side out, I felt saddened and overwhelmed by the multitude of her experiences but yet completely consumed by her capacity for resilience, and her wish to share her story and teach others. I found my position an interesting one, I felt like I was bearing witness to her atrocities yet at the same time was being asked for acknowledgment of how well she had coped and what a survivor she was, I also felt in a struggle about my role as a researcher and the clinician within me who has such an interest and experience of working with women in similar situations felt shut down and restricted, I wanted to give her more than the interview slot I had. I felt honoured to be hearing such a story and found myself thinking about the power of her words and how they could reach a wider audience. At the end of the interview she embraced me and told me what a wonderful experience it had been talking to me, I felt relieved and had a reinforced energy for my research.

March 18th 2010

A women started telling me about many experiences from health professionals of stigma and discrimination which she had faced, I felt sickened at some of her accounts and frustrated and disappointed that this was taking place in England. It took me back to some of the stories I used to hear when I was in Africa and made me wander about how it was safer for me to associate them there, than to bear the thought of them still happening in a context which I was part of. I wandered what my role meant or represented to her, here I was a white professional talking about her HIV. I felt my attempts to be warm, supportive and containing increase minute by minute as a way of giving her a different type of experience from a professional. I also was inspired by her ability to reflect on the more positive health professional experiences, and her wish to change and improve things as opposed to punish or resent them.

April 20th 2010

Today I interviewed 3 women and was struck by all of their vivid accounts of the difficulty of not breastfeeding. This felt something that was really important and caused them a great amount of distress. They spoke a lot about the lack of connection to their baby, the cultural ideas around not breastfeeding meaning you were not a good mother or were selfish, or how it indicated to others that you were HIV-positive. They spoke about the importance of breastfeeding as an African mother and how it signified being womanly. This felt like something I anecdotally had experienced through my trips to Africa but hadn't seen fore

grounded in the literature, I wondered whether my interest in this area had shaped my questions in which led the women to share their feelings on breastfeeding. I also had felt this though with medication, in my experiences of talking to women diagnosed in Africa many had concerns about the medication, that it was unnatural, going against the spirits that G-d would heal them etc yet so far none of these concerns had come up the medications and therefore did not seem pertinent to these women.

March 7th 2011-05-14

Sitting trying to cut thousands of words from section B and feeling really frustrated, I want to have it all in there especially as I felt the women's voices so rarely get heard that I feel a responsibility and wish to change this. Trying to use one or two quotes from so many rich accounts feels torturous but equally feel I am learned a lot about research, the importance of condensing, being concise and selective. Whilst writing the paper I am very aware of what a small slice of the pies readers get to taste and am left thinking about what the women will think about the way I have captured their stories.

Appendix 15- Rolfe et al. (2001) Reflective model (model used to aid ongoing reflection)

Descriptive level of reflection	Theory - and knowledge - building level of reflection	Action-orientated (reflexive) level of reflection
What ...	So what ...	Now what ...
... is the problem/difficulty/ reason for being stuck/reason for feeling bad/reason we don't get on/etc., etc.?	... does this tell me/teach me/imply/mean about me/my patient/others/our relationship/my patient's care/the model of care I am using/my attitudes/my patient's attitudes/etc., etc.?	... do I need to do in order to make things better/stop being stuck/improve my patient's care/resolve the situation/feel better/get on better/etc., etc.?
... was my role in the situation?		
... was I trying to achieve?		... broader issues need to be considered if this action is to be successful?
... actions did I take?	... was going through my mind as I acted?	
... was the response of others?	... did I base my actions on?	... might be the consequences of this action?
... were the consequences	... other knowledge can I bring to the situation?	
· for the patient?		
· for myself?	· experiential	
· for others?	· personal	
... feelings did it evoke	· scientific	
· in the patient?	... could/should I have done to make it better?	
· in myself?		
· in others?	... is my new understanding of the situation?	
... was good/bad about the experience?	... broader issues arise from the situation?	

Appendix 16: Dissemination and End of Study Letter Salomons Ethics Panel

Title

The experiences and meaning for African women living in the UK after being diagnosed with HIV during their pregnancy.

Brief summary of the Rationale for the Study

Given the increasingly high proportion of African mother's living with HIV/AIDS in the UK (Flowers et al., 2006) and the Department of Health (DoH) and NHS's focus on delivering cultural competence (DoH, 2005), it is surprising that there is a dearth of literature exploring their needs and experiences. Taking into account the re-conceptualisation of HIV as a chronic illness (Clarke, 1994), the availability of medication in the UK, and associated increased life expectancy, more consideration is required to explore these women's quality of life (QOL) issues, coping styles, and lived experience. Whilst deductive quantitative approaches may be useful in the future, the existing literature neglects the relational and psychosocial lived experience of African mothers in the UK, who are often refugee or asylum-seeking women diagnosed with HIV during their pregnancy. Their complex plethora of experiences is indicative of the need for a more in-depth qualitative exploration, owing to the significance of maternal wellbeing on child outcomes, the mother-child relationship, and early intervention opportunities.

Research Question

"What are the experiences and how do UK-based African women perceive, make sense, and manage a diagnosis of HIV during their pregnancy, and subsequently?"

This study hopes to extend current understanding on how best to support this population, both at the time of diagnosis and subsequently, and to inform useful life-enhancing psychological models.

Sample

The purposive sample included 12 participants. All participant's were: 1) female, 2) self-identified as African, 3) over 18-years, 4) living in the London vicinity, 5) had or were attending an HIV-antenatal group, 6) diagnosed with HIV during their pregnancy, 7) able to communicate verbally in English, and 8) willing to participate. Participants who did not meet these criteria were not approached and therefore were excluded.

The participants were aged between 23-41, with a mean age of 32. Their length in the UK ranged from 2 to 19 years, with a mean of 8 years. Time since diagnosis ranged from 10 months to 7 years, with a mean of 5.2 years. They were from a variety of African countries and had a range of employment and marital statuses, educational qualifications, and were from a array of religious and cultural backgrounds. Immigration status varied, however the majority were asylum-seeking women.

Method

This study used a non-experimental, qualitative design. The information was collected using semi-structured interviews.

Summary of key findings

Themes which emerged were around HIV being part of one's wider tapestry, community and systemic influences and responses to HIV, experiencing a different story of HIV, the mother-child relationship and one's capacity for resilience. Some key challenges and coping strategies are outlined.

Implications for future research

Further exploration of the role of fathers and siblings in this area is needed. Furthermore, future studies would benefit from investigating these women at different illness stages, as well as comparing them to non-asylum-seeking/ refugee women to establish the optimal interventions to identify and meet their varying needs. It would also be clinically useful to explore differences or emerging themes in those women who have become pregnant and/or contracted HIV from rape or whose children are HIV-positive. Moreover, the above findings could be explored using psychometric measures on areas including stigma, mother-child attachment, illness perceptions, coping and resilience.

Implications for practice

Several suggestions are made, however some key ones are as follows: 1) designing and carrying out awareness campaigns and training with health professionals and the media, 2) working with people using a holistic formulation which takes into account the numerous factors these women face in addition to a diagnosis of HIV, 3) attending to interpersonal difficulties around disclosure decisions and of not breastfeeding, 4) creating more opportunities to attend support groups and to link in with various services, including religious and spiritual ones, 5) to find ways for people to be experts of experience through helping others or having an active role in their condition, and 6) supporting people in meeting and witnessing others who are doing well and living healthy.

Appendix 17- Respondent feedback/ dissemination

The researcher was invited to attend one of the antenatal groups where she had initially recruited participants to discuss the findings of the study and to hear the women's thoughts on the study. The below is a brief summary of some of our informal discussions:

Six of the 12 women who participated in the study were present, and an additional 3 new to the group women were present.

The feedback was overwhelmingly positive and the women who took part reported on finding the participation a “worthwhile/ enjoyable/ thought provoking/ caring/ positive” experience.

The majority of women stated that they were pleased to see HIV on the agenda in this case, and to have their voices heard; they reported feeling strongly about themes around breastfeeding, experiences of stigma, previous trauma experiences, psychosocial stressors and of the power of meeting other people.

They voiced particular interest in the recommendations, and strongly hoped that more training and awareness campaigns would be formed in the future. They realised this was challenging and hoped that if lots of research kept on taking place, which they were keen to be involved in, that this would be moving in the right direction.

They also would be interested in how different the findings would be if the study was carried out in Africa, and this sparked conversations of cross-cultural research. They also thought it was important that women new to the UK with Africa had ways of learning and knowing that HIV in the UK is different to HIV in Africa.

They also were interested in finding out more from partners, family members and their children's perspectives, and seemed to feel this would add to the richness of the findings.

They were also struck by the attention paid to strengths and capacity to resilience, and stated that this felt “special/ rare/ different”.

For the women who were not in the group and who had indicated they wanted to know the findings, a copy of the study will be sent to them (via a method of their choice) following the completion of the doctorate (they were aware of this timeframe), and a summary will be made available to them earlier.

As initially agreed with the charity, 2 copies of Section B will be provided following completion of the doctorate so that the women, facilitators etc can have easy access to the findings.

Appendix 18- Salomons Ethics Approval

Removed to ensure confidentiality

Appendix 19: Journal selected for submission

Removed prior to binding.